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Evaluation of Information Acquisition and Information Retention Using a Low-literacy Booklet for Illiterate Caregivers of Children with Leukemia

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EVALUATION OF INFORMATION ACQUISITION AND INFORMATION RETENTION USING A LOW-LITERACY BOOKLET FOR ILLITERATE CAREGIVERS OF CHILDREN WITH LEUKEMIA

by

Terezie Tolar Mosby

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DEDICATION

I would like to dedicate this dissertation work to my family.

To my children Vojta and Nicholas, who were born during my undergraduate studies in Prague, Czech Republic. During all their life, I have been at school ending now with the doctorate degree in Memphis, TN. Vojta is 14 years old and Nicholas is 12 years old. The next 14+ years, I am planning to focus on their education and helping them as much as I can to reach their goals.

To my parents for always being examples of courage and for helping and supporting me on this journey.

To me for not giving up.

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ABSTRACT

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At the 2006 meeting of the Asociación de Hemato-Oncología Pediátrica de Centroamerica y Caribbe, local nurses recognized food safety as one of the main problems they dealt with daily. Based on that information, food safety education program was developed. The program consisted of development, evaluation, distribution of the booklet "*Alimentación del niño con cáncer* [Feeding the child with cancer]", training of nurse educators to provide food safety education using the booklet, and testing of its efficacy. Development of the booklet included a survey in Guatemala and El Salvador hospitals and its review by a board of experts. Pre- and post-education tests were developed and validated by a board of experts. An Educators' speech was developed for consistency of education as well as a demographics questionnaire. The efficacy of the booklet was tested with 162 caregivers of patients with newly diagnosed leukemia in Guatemala and El Salvador. The demographics questionnaire revealed that more than 30% of caregivers did not have refrigerator to store food, 22% did not have a stove and 74% did not have a microwave. Eighty two percentages of families drank water which was not safe for a patient. The Wilcoxon Signed Ranks test was used to evaluate knowledge acquisition and retention after education with the booklet. Information retention was tested 1 month and 3 months after initial education. The *Alimentación* booklet was found to be efficient to educate about food safety ($p < 0.0001$). There was no significant difference between post- educational knowledge in El Salvador and Guatemala at 1 month ($p = 0.0918$ and $p = 0.0781$) and at 3 months in Guatemala ($p =$

0.3125). Pre-educational knowledge was not associated with any tested demographic variable except for self-reported ability to read in El Salvador ($p = 0.0145$). There was no significant association between information acquisition and demographic variables within each country. Caregivers from El Salvador had a better information acquisition than caregivers from Guatemala ($p < 0.0001$). Education using the low-literacy handout greatly improved food safety knowledge, which remained high 1 and 3 months after initial educational intervention.

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INTRODUCTION

Since its opening in 1962, the St. Jude Children's Research Hospital (SJCRH) has contributed to the increase in the survival rate of children with cancer and other catastrophic diseases. Childhood cancer is a treatable disease in high-income nations. The cure rate for the Acute Lymphoblastic Leukemia (ALL), the most common neoplasm in children, is higher than 90%. In low-income countries, where 80% of the world's children live, the survival rate for children with cancer is minimal (Howard et al., 2007). The mission of the International Outreach Program (IOP) at the St. Jude Children's Research Hospital is to increase the survival rates of children with cancer living in low income countries through the sharing of knowledge, technology, and organizational skills (IOP, 2011). The IOP at the St. Jude Children's Research Hospital partners with 20 institutions; most of them are in Latin America, specifically in Central America.

One of the reasons for the low survival rate in low-income countries is the high incidence of infections in patients treated for cancer. Patients undergoing anticancer therapy, including chemotherapy, are at a higher risk for acquisition of foodborne illnesses, particularly those of infectious etiology (Angele, Loehe, & Faist, 2005; Forest, 2004; Wang & Deng, 2007). This risk is due to an immune suppression caused by chemotherapy. To prevent infections from food, medical experts recommend that patients follow strict adherence to food safety procedures during chemotherapy treatment. In countries with high food safety standards, such as the United States of America (U.S.A), Canada, and western and central Europe, the trend is to make this diet more flexible and allow patients to eat a greater variety of foods, because the chance of bacterial

contamination from food is very low. On the other hand, in countries with hot climates and low food safety standards, the chance of bacterial contamination from food is much higher and, therefore, the recommendations of experts working in pediatric oncology outreach are to follow the diet strictly to prevent foodborne illnesses.

El Salvador and Guatemala are countries with hot climates and a large percentage of the population living below the poverty level. The proposed study is based in two public hospitals, one in El Salvador and one in Guatemala, where low-income patients are treated. Because anticancer treatment is usually several months long, it is very important that the patients and/or caregivers are well educated about food safety guidelines, so they have an ability to make safe food choices (Moody, Finlay, Mancuso, & Charlson, 2006). In El Salvador and Guatemala, caregivers also face a challenge of having limited facilities to cook and store food at appropriate temperatures. Therefore, one purpose of this study was to determine cooking and food-storage facilities and water supply available to the study populations in order to be able to provide the most appropriate education and advice.

Table 1

Compare El Salvador and Guatemala

Indicator	El Salvador	Guatemala
Under-5 mortality rate, 2009	17	40
Infant mortality rate (under 1), 2009	15	33
Total population (thousands), 2009	6163	14027
GNI per capita (US$), 2009	3370	2630
Life expectancy at birth (years), 2009	72	71
Total adult literacy rate (%), 2005-2008	84	74
Primary school net enrolment/attendance (%), 2005-2009	94	95

The director of the IOP Nursing Program, and the principal investigator for this study were among the St. Jude Children's Research Hospital attendees at the tenth meeting of the Central American Association of Pediatric Hematology-Oncology (Asociacion de Hemato-Oncologia Pediatrica de Centro America, AHOPCA) in February 2007. Health professionals from the Dominican Republic, Guatemala, Panama, Honduras, Costa Rica, El Salvador, Nicaragua, Italy, Spain, Canada, and the United States met to discuss the treatment of pediatric oncology patients residing in AHOPCA countries. During the conference, fourteen nurses representing seven countries met to discuss obstacles and brainstorm ideas to address the nutritional management of the pediatric oncology patients at the respective institutions (Mosby et al., 2008).

Three obstacles identified by the AHOPCA nurses were: A limited availability of nutritionists to provide nutritional education for patients and families, an ingression of unsafe foods by immuno-compromised patients delivered by their parents, and a lack of nutritional educational materials for caregivers, many of whom were illiterate or had low-literacy skills (Mosby et al., 2008). A survey of the attending nurses showed that the lack of educational materials had resulted in confusion about safe versus unsafe foods and food preparation techniques that are imperative for pediatric oncology patients undergoing treatment. It was hypothesized that providing simple but specific information about food safety to caregivers would have a positive impact on decreasing foodborne infections. To address the lack of culturally appropriate food safety educational materials suitable for caregivers of cancer patients, an eight- page, color illustrated educational tool "Alimentación del niño con cáncer" ("Feeding the child with cancer") was developed (Garcia, Chismark, Mosby, & Day, 2010). Henceforth, this educational tool will be called *Alimentación* booklet. This nutritional education booklet teaches the caregivers to exercise a more cautious approach to choosing and bringing food into the hospital and preparing meals for their children at home. This booklet outlines specific steps to ensure food safety. It is designed for low-literacy caregivers of pediatric oncology patients in Guatemala and El Salvador. This booklet consists mainly of pictures and very few words.

In the development of educational material, the focus was on visual attractiveness by using colorful pictures. This booklet was intended to be appropriate for use by low-literacy adults as well as by children. Cultural appropriateness was secured during development of the handout by interviewing healthcare professionals and patients about their eating and cultural habits and using only food, which is commonly eaten by this

population. An educational speech was developed and delivered by the nurse educator when meeting with the patient's caregiver. This speech, which was memorized by nurse educators for consistency in education, was interactive, asking questions and requesting active participation of caregivers.

The primary purpose of this study was to test efficacy of this booklet, as an educational tool for low-literacy population. A pre-test and post-test were administered to test information acquisition. To test information retention, the post-test was repeated 1 month and 3 months after the primary education. The secondary purpose was to identify, which variables affect information acquisition and information retention in the study population. The long-term goal of this study was to decrease foodborne illnesses in the population of children with leukemia and thus improve treatment outcomes (De Rivera, Amador, Mourra, Li, & Rasheed, 1995; Frenkel et al, 1995). However, evaluation of long term objectives was not a part of this research.

Background of the Problem / Pilot Study

Discussions during the 10th meeting of the Central American Association of Pediatric Hematology-Oncology (AHOPCA) determined that food safety education materials were not available in Central American countries. As a result, patients and their families were uncertain about safe versus unsafe foods and their preparation techniques. AHOPCA nurses identified the limited availability of nutritionists to provide nutritional education for patients and families, the ingression of unsafe foods for immuno-compromised patients prepared by their parents, and the lack of nutritional education materials for caregivers, many of whom were illiterate or low-literate, as major obstacles

to the nutritional management of children with cancer. Based on those findings *Alimentación* booklet was developed.

To assess efficacy of the *Alimentación* booklet, pre- and post-tests were used to measure information acquisition and retention by caregivers in Guatemala and El Salvador. The test contained 10 multiple-choice questions and content was validated by a team of experts. The test was administered by nurse educators trained to provide food safety education using the *Alimentación* booklet. The pre-test was administered prior to the educational intervention. The post-test was administered immediately after education intervention, and again after 1 and 3 months. Twenty-six caregivers participated in the pilot study. Since the caregivers had a low literacy level, the nurse educators helped them to complete the pre-test. Each caregiver also completed a demographic questionnaire. A nurse educator met with each family separately to teach them about food safety using the *Alimentación* booklet. Each nurse educator followed a script prepared by the principal investigator. After going through the *Alimentación* booklet, the nurse educator asked the caregiver to complete a post-test, which was identical to the pre-test. Each caregiver was reeducated and retested at the following intervals: after 1 month and after 3 months of child's treatment for cancer.

The mean test score of caregivers increased from 4.50 ± 2.4 to 8.77 ± 1.7 after the educational intervention ($p < 0.001$). The mean test scores at 1 and 3 months after the educational intervention were 8.20 ± 2.3 and 8.33 ± 2.1, respectively.

The educational intervention provided by nurse educators using the *Alimentación* booklet significantly improved food safety knowledge and knowledge levels were sustained at 1 and 3 months post intervention (Mosby et al, 2009).

Based on the pilot study, several changes were made. First, the results of the pilot study showed minimal difference in knowledge retention one month after the educational intervention and no difference three months after the educational intervention. Therefore, post-test at 3 months was omitted to simplify the study. Second, changes were also made to the *Alimentación* booklet to include more local foods. Third, modifications were made to pre- and post-tests to make some questions more clear to caregivers. Their content was not changed. Fourth, soda was removed from the *Alimentación* booklet. Although soda is commonly consumed by pediatric patients in local hospitals, it is an unhealthy option and, therefore, was excluded from the booklet. The word "cancer" was taken out of the title of the booklet. Some caregivers suggested that it is a too strong word which many times mean death. The word "cancer" was replaced with "dietary recommendations for children with low immunity".

Statement of the Problem

In developing countries, problems surrounding education of patients and families are compounded due to shortages of trained staff, lack of accessible facilities, overcrowding, issues of poverty, and low education and literacy levels (Hubley, 2006). There are also great socio-economic, educational, cultural, and linguistic disparities between patients and healthcare providers in developing countries (Ngoh & Shepherd, 1997).

Public hospitals in low-income countries (especially in the Central American countries, where this research was conducted) serve the majority of patients from low-income families and with a low-literacy level. In private hospitals, the patients have to pay for their treatment, thus generating an income for the hospital to develop educational

materials. The government - run public hospitals accept patients without insurance and without ability to pay. These hospitals face a constant financial struggle. Regarding children's health in the low-income countries, the main focus is on infectious diseases including diarrhea, malaria, tuberculosis and HIV. Pediatric oncology is not a healthcare priority. Therefore, governmental funds are not spent on this problem.

Caregivers' illiteracy rate in the public hospitals is high due to the fact that the main caregiver is usually a mother of the child. Women in low-income countries have poorer access to education than males. Two-thirds of all illiterate people around the world are women (The Impact of Literacy, 2008). If an impoverished family had to choose between sending a daughter or a son to school, they would most likely send a son. In many countries, women are viewed as inferior to men, as merely domestic help and child bearers therefore, not in a need of an education.

A study in China has shown that a mother's education is an important predictor of a child's health. A large sample of adopted children was studied. As adopted children are genetically unrelated to the nurturing parents, the educational effect on them is most likely to be the effect of nurturing. The mother's education was an important determinant of the adopted child's health even after controlling for other parameters, like income, number of siblings, health environment and other socioeconomic variables (Chen & Li, 2009).

An illiterate caregiver is exposed to additional stress and, possibly, a poorer treatment outcome. Many health care providers are not prepared for caregivers who are illiterate. Because they are not prepared for illiterate caregivers, illiterate caregivers may feel incapable and inadequate. The main problem is the patient's safety. The caregiver

who is illiterate and is not provided with a proper educational material may forget key points of the patient's treatment. An illiterate caregiver may feel embarrassed to ask questions regarding treatment, about which he/she could otherwise read in the educational material. Many times, the illiterate caregiver does not say upfront that she/he is illiterate, because it is embarrassing for her/him in a facility, where everybody has a high literacy level and a high literacy level is automatically expected. Healthcare providers, on the other side, never ask questions about the literacy level of a caregiver. High literacy level is expected in hospitals in high income countries making a question about illiteracy bizarre. Usually, illiteracy comes up when a treatment is already in process and some misunderstandings have occurred.

In developing countries, illiteracy is common, and not unexpected in a low-income population. Many times, the low-income class is perceived as uneducated, violent and not caring. Freire stated: "Concerns of humanization lead at once to the recognition of dehumanization, not only as an ontological possibility but as an historical reality (p.38)." The low-income class in developing countries is often de-humanized. According to Freire, dehumanization is a distortion of being more fully human. This fact is commonly seen also in the hospital settings. "Common people" are never seen as "the oppressed" but – depending on whether they are fellow countryman or not – "those people" or "the blind and envious masses" or "savages" or "natives" or "subversives" who are "disaffected", who are "violent", "barbaric", "wicked," or "ferocious" when they react to the violence of the oppressors" (Freire, 1921, p. 38). Conditions, which the higher class finds to be inappropriate for themselves, are acceptable for the low-income class. This includes higher mortality rates, substandard living conditions and illiterate

status. Furthermore, the low-income population is perceived as completely responsible for being in situations including poverty, inadequate education and poor health care. Low- and high-income classes rarely interact in some countries. Children from high-income families go to private schools, are treated in private hospitals and live in privileged locations. Children from low-income families are treated in public hospitals and go to public schools, if they go to school at all, and live in slums many times surrounded by high walls.

Because of the low survival rate of pediatric patients with cancer in the public hospitals in low income countries and also because of a low healthcare literacy of caregivers, many caregivers do not choose hospital treatment as the first option, but go to a traditional healer instead. Traditional healers usually find a reason for a child's disease, something that cannot always be said about conventional medicine. Reasons for a child's disease may be an envy of a family member, some bad deed committed by a family member or a curse. The traditional healer may offer a medication in a form of an herb preparation or a prayer, while public hospitals often struggle with having an appropriate medication available. The traditional healer is usually from the same socio-economic class as the caregiver. Therefore, caregivers are not likely to feel inferior as they would in public hospital setting, where medical personnel come from a higher income class than the patients and caregivers themselves.

Another reason for preferring traditional healers is that they are available in the same location. Family does not have to travel a long distance to a pediatric oncology unit in a hospital located in the city. Usually, there exist few such hospitals in the whole country. When the treatment by a traditional healer shows no effect, caregivers start

looking for a medical treatment. By that time, cancer is already widespread and there is only a minimal hope for a patient's cure. Caregivers, due to their world view, may believe that a patient's life is entirely in God's hands and that it is up to God's will, if the child was going to live or not. They may decide not to use their limited resources to provide a patient with a medical treatment. Many times, a child's life is sacrificed for well-being of other children in the family. Abandonment of treatment for girls is seen more often, because girls are not considered to have the same value as boys. Unfortunately, the community, in which the patient lives, does not help either. In many cultures, sickness is seen as a curse or a sign that either the mother or another member of the child's family did something wrong and, therefore, the sickness is deserved.

It is difficult to improve the current healthcare situation in the developing countries. Many times, a lack of finances is to blame. Some hospitals have improved the survival rate by implementing very low-cost tactics. For example, in Malawi, the pediatric oncology unit is providing two bags of rice and a can of plum butter (a peanut butter) to a child's family every two weeks when the caregiver arrives with the patient to the hospital to receive treatment (Hesling P., 2010). This tactic has decreased abandonment of the treatment significantly. In Guatemala, a van picks up patients at their homes and takes them to the hospital for treatment. After treatment, the van returns them to their homes. There is no cost for this service. Many times, the cost of transportation is the main reason for treatment abandonment, because families live several days of travel from the hospital and lack money for transportation. Some hospitals depend on a constant financial income provided by grants from high-income countries or foundations supporting such programs.

From the research, is known that literacy and education are important factors in healthcare. According to Freire (1921), "implementation of a liberating education requires political power and the oppressed have none" (p. 36). The *Alimentación* booklet developed for the study serve as the first step of a liberating education. When the caregivers are educated about food safety they can make more educated choices about the food they offer to their children and prevent them from getting sick.

Another way to improve healthcare literacy is to use healthcare educators. In many developing countries, this has already been practiced. Nurses or other healthcare providers go to the communities with photographs of cancer signs informing parents where to send a child, who has signs of cancer. Cancer of children in low-income countries often goes unrecognized for many weeks or months. For example, in some African countries, the signs of leukemia are very similar to the signs of malaria. The difference between malaria and leukemia can be recognized by a simple blood test. But it is costly. Children with signs of malaria are treated for malaria. Only when the treatment is ineffective, the child is sent to a hospital for additional tests. Many times, it is already late. Knowledge about child cancer can also be increased by having parents of children with cancer serve as educators, to educate teachers at schools and also to educate traditional healers.

Literacy plays multiple roles in health care. Illiterate populations have a poorer health. Children cared for by illiterate mothers are less healthy. Two thirds of illiterate adults are women. For these reasons, measures improving education and literacy should be focused on women as natural caregivers of children. Women's literacy will improve their own health, the health of their families and of their children.

Purpose

Purpose of the study was three-fold:

Primary Purpose:

1. Test efficacy of *Alimentación* booklet, as an educational intervention for low-literacy population. Use a pre- and post-test to determine information acquisition and information retention.

Secondary purpose:

1. Determine available food storage, cooking facilities, and water supply available to the caregivers

2. Identify which variables affect pre-intervention knowledge, information acquisition and information retention in the caregivers

Long-term goal:

The long-term goal of this study was to decrease foodborne illnesses in this population and, therefore, improve treatment outcomes (the long-term goal was not tested).

Definitions of Terms

Caregiver: Caregiver is an adult who is responsible for patient and brings patient to the hospital for visits. It can be mother, father, grandmother or grandfather, sister, aunt, or any other person responsible for the patient.

Treatment: Treatment is a medical care received by the patient to treat cancer.

Educational Intervention: Education received by the caregiver regarding food safety using *Alimentación* booklet.

Instrument: Demographic Questionnaire, Pre- and Post-test

Nurse Educators: Researchers performing data collection and providing educational intervention using *Alimentación* booklet.

Chapter 2

LITERATURE REVIEW

Literacy in Healthcare

Literacy does not mean only to be able to read and write, but also to be able to use the written language to participate in activities of the community and of wider society. Illiteracy and low-literacy is common around the world, but also in the U.S.A where it is less expected. Illiteracy is an important problem in the United States of America and worldwide. According to the U.S.A. Department of Education's 2003 statistics, about 14% of the U.S.A. population lacks the Basic Prose Literacy Skills (BPLS). This is one in seven Americans (National Assessment of Adult Literacy, 2003). Worldwide in 1999, 774 million people are illiterate and two thirds of the world's illiterates are women (The Impact of Literacy, 2010). The percentage of the illiterate population increases significantly, when the focus is on the developing world only. According to the 1999 United Nations Children's Found (UNICEF) report, only 80% of the world's adult population is literate. That means that every fifth person on the earth is illiterate and has never attended a school. Per UNICEF 1999 report literate persons live in more desperate poverty and poorer health than those who can read and write.

Definitions of Literacy

The definition of literacy has changed over the years. At one time, being literate meant to be able to sign your name. Later, being literate meant to be able to read and write in Latin. Today, being literate means that you can read and write in your native language. The United Nations Educational, Scientific and Cultural Organization (UNESCO) define literacy as the ability to identify, understand, interpret, create,

communicate, compute and use printed and written materials associated with varying contexts (UNESCO, 2004). Literacy involves a range of learning that enables individuals to attain their goals, to develop their knowledge and potential, and to participate completely in their community and wider society (UNESCO, 2004). Definition of literacy states that a 15-year-old person is able to read and write (NationMaster, 2010). A simplified definition of illiteracy describes it as a condition of being unable to read and write. Healthcare literacy is "an individual's ability to read, understand and use healthcare information to make decisions and follow instructions for treatment" (Health Literacy, 2010). Studies have shown that approximately half of all patients in the U.S.A. cannot understand basic healthcare information. Misunderstanding healthcare information reduces the success of treatment and increases the risk of medical error (Health Literacy, 2010). Low literacy or a limited literacy is defined as an inability to read or write well enough to perform necessary tasks in the society or on the job. There is not exact definition of high literacy but under high literacy can be expected to have literacy level above 7th grade.

Literacy always exists in a context. For example, healthcare literacy is the ability to understand terms and ideas related to health and exists in the context of healthcare. Computer-technology literacy is ability to understand terms related to computers and other technology associated with computers and exists in the context of using a computer.

Role of Literacy in Adult Learning

Literacy plays an important role in adult learning but is not a requirement for adult learning. The history of written communication goes back to 30,000 years ago, when symbols were used for communication (Ravilious, 2010). Writing is 7,000 years

old (Fischer, 2003). The concept of literacy appeared as early as the 15th century, when a type-printing press was invented and a written language was made available for a selected population in Europe. During the 20th century, learning from a written language has become more dominant than ever before. In many cultures, literacy is now expected and adult learning is often based on the requirement of being able to read and write. For example, literacy increases job opportunities and the likelihood that a student will be admitted and successful in higher education.

Historically, literacy was also used for a control of power. By being able to read and write one can increase its knowledge which may increase his/her potential for self defense. For example, slaves were not allowed to go to school to learn how to read and write in order to prevent them from gaining power. Paulo Freire, the important figure in adult learning, was exiled from Brazil because he taught peasants how to read and write (Lownd, n.d.). In his book "Education as a practice of freedom," Freire emphasized education for literacy as an act of culture and freedom (Freire, 1976).

Role of Adult Learning in Literacy

Literacy plays an important role in adult learning by providing access to education and resources. An adult who is not literate may achieve literacy by becoming an active learner. Knowles (1973) identifies several characteristics of an adult learner: adults are autonomous and self directed, have accumulated life experience and knowledge, are goal-oriented, are relevancy-oriented, are practical and desire respect. For example when child is nauseated and vomiting, a caregiver seeks advice from the nurse (autonomous and self directed), adults have some experience in caring either for their younger siblings or elderly parents or for their children, therefore they are usually experienced caregivers and

know at least partially what to do regarding child care (accumulated life experience and knowledge). Mother's goal can be to provide the best care for her children (goal-oriented), when the child is sick a mother will seek information about the particular disease from the internet or from other mothers (relevancy oriented).

Several national and international institutions focus on adult literacy. Some of the national institutions are National Institute for Literacy, The Literacy Project, and Literacy Connections. Organizations which are focusing on improving literacy around the world are Kiwanis International, World Education Forum, UNICEF and many others. The goal of many international literacy agencies is to improve life of people by improving their literacy. The literacy and the right to education have been included in the Universal Declaration of Human Rights (United Nations, 1948).

Immigrants display a special kind of illiteracy. They may be literate in their native language, but can be illiterate in the language of the country in which they are living. In the present time of global economy and increased migration of people, immigration is an important political and economical fact and each country has to find a way to deal with it. There is no doubt that education is an important factor improving assimilation of immigrants.

In the year 2000, 31.1 million immigrants lived in the U.S.A. In 2000 every fifth child born in the U.S.A. was a child of an immigrant (Reardon-Anderson, Capps, Fix, 2002). About 12% of the U.S.A. populations are immigrants. Many countries have a much higher percentage of immigrants. For example, 77% of the population in Andorra, 66% of the population in Kuwait, and 71% of the population in United Arab Emirates are immigrants. Proportions of immigrants in populations of European countries are

Germany 12%, Ukraine 14%, Switzerland 23%, France 10%. Immigrants living in Canada constitute almost 19% of the population (United Nations, 2006).

The rates of low-literacy in general population for the year 1998 are 49.6% in USA, 43% in Canada, 42% in Germany (NationMaster, 2010). Even reliable U.S.A. agencies, such as Pro-Literacy World-Wide, claim that a high illiteracy level in the adult U.S.A. population is due to immigration. The President of Pro-Literacy World-Wide said that a high illiteracy rate in the U.S.A. is caused by three demographic trends — immigration, student mobility, and school push-outs. The causes leading to illiteracy in the U.S.A. may be more complex. The U.S.A. neighboring country, Canada, has a higher percentage of immigrant population, but a smaller percentage of low-literacy population.

Many immigrants come to the U.S.A. with a degree from a college or university and actually immigrate to continue their education. In the school year 2008-2009, 671,616 international students were in the U.S.A., an increase of 8% compared to the figure for the previous year (US Department of State, 2009). The number of new international students increased by 16% from the total of all international students. Some of those highly educated adults intend to seek permanent residency in the U.S.A.

Illiteracy definitely puts people at a disadvantage for obtaining such things as employment, education, and healthcare resources. With respect to the immigrant population, Lindeman's question seems to be very appropriate: "What kinds of adjustment are being required of individuals? … In what ways can education aid and accelerate the adjusting process?" (Lindeman, 1961, p. 93). Currently, classes of English as a Second Language (ESL) form 87% of pro-literacy America's community-based programs and provide the kind of education to which Lindeman refers.

Importance of a Literacy Level in Healthcare

This study focused on the development of educational material for illiterate or low-literacy adults caring for children with cancer. At SJCRH, all caregivers and patients, which are at risk for acquiring foodborne infection, are educated about the neutropenic diet immediately after diagnosis or at least 72 hours after admission to the hospital. Neutropenic diet is a low bacteria diet for patients with low neutrophiles count. Neutrophiles are precursors of white blood cells responsible for immune defense. All neutropenic children at risk which are admitted to the hospital are placed on the neutropenic diet and are given the neutropenic diet menu from which to choose their food. This dietary prescription is also recorded in the main hospital kitchen on a card file. Should the child or caregiver order food which is not in agreement with the neutropenic diet, the food will not be sent to them. There are several additional check points and follow-ups during their hospitalization to ensure that any mistake regarding compliance to this diet is not made. At St. Jude, all handouts, including this neutropenic diet, are written at a 4^{th} grade reading level. The majority of caregivers and patients in the St. Jude Children's Research Hospital have a high literacy level. Occasionally, however, because St Jude Children's Research Hospital also takes international patients, caregivers are illiterate or have a low-literacy level.

In 2007, there were no educational materials available for illiterate patients in SJCRH. While there were educational materials available in different languages, there were no educational materials for illiterate caregivers. One particular caregiver had a very good memory, was very committed to the child, and had a high intelligence level (IQ) despite her illiteracy. She illustrates that literacy is not associated with IQ level but

with access to education. Medical personnel taking care of this patient had to find a new way to communicate and determine how to help the caregiver remember things without using a written language. For example, color coding the pill box helps the caregiver remember which pills to give the patient. Additional time is spent explaining things which otherwise would be given in the form of a written handout.

Food Safety and Low Bacteria Diet Instructions

In developing countries, such as those in AHOPCA, the prevalence of malnutrition in children with cancer at the time of diagnosis averages 50% (Sala, Pencharz, & Barr, 2004). In addition to malnutrition, children diagnosed with cancer have an increased risk of infection, the leading cause of death in all cancer patients (Todd, Schmidt, Christain, & Williams, 1999). At St. Jude Children's Research Hospital, caregivers and patients are educated on food safety and a low-bacteria diet. The introduction of bacteria and contaminants into the gastrointestinal tract can be reduced by practicing strict food safety and excluding certain foods from the diets of immunocompromised patients (Todd et al., 1999).

These preventative measures can reduce the risk of food poisoning or infection (Todd et al., 1999). Safe food practices have the potential to prevent complications during treatment, but this information may not be accessible to caregivers in underdeveloped or developing countries. When low-literacy patients and caregivers receive spoken medical instructions and picture-based materials, research on cued recall suggests that home care can be significantly improved (Houts, Doak, Doak, & Loscalzo, 2006). These materials may reduce the need to rely on printed text for health instructions (Houts et al., 2006).

Using Informational Handouts

Pediatric oncology patients and caregivers are often overwhelmed with information upon diagnosis and throughout treatment, including information regarding proper nutrition and food safety. Studies have demonstrated that patients remember only 29% to 72% of the information verbally presented by health professionals (Houts et al., 1998). Health professionals frequently rely on informational handouts to enhance understanding and recall of medical instructions. Printed materials are easy to store, require no special equipment, can be used as reference materials outside the hospital setting, provide a means for transmitting standardized information to patients, and may be tailored for specific audiences (Zimmerman, Newton, Frumin, & Wittet, 1989). However, many existing handouts have a high readability level which means on or above 7th grade level. These handouts may be ineffective when working with illiterate or low-literate caregivers and clients. Handouts with high reading level result in diminished perceived benefits of materials, hindrance of client self-care, and a compromise in the quality of care (French & Larrabee, 1999).

Review of Research

One study assessed factors that influence nutritional education of parents with low-literacy levels (Macario, Emmons, Sorensen, Hunt, & Rudd, 1998). Researchers interviewed 35 literacy experts physicians, nurses, and nutritionists, in addition to 50 clients from an adult basic education program. They found that although most providers and patients recognize that patients perceive physicians to be the authorities on health, patients with low-literacy skills turned first to family members and friends for health information. This finding indicates that effective nutrition education must build on

patients' social networks, appear in a visually-based, interactive format, and be culturally appropriate.

Assessing information acquisition and information retention of the learners is helpful in determining the effectiveness of the educational tool. One study looked at information retention and information acquisition using a low-literacy, multimedia education tool designed to promote asthma care among African American adults (Sobel, Paasche-Orlow, Waite, Rittner, Wilson, & Wolf, 2009). Researchers used a pre and post-test to assess information acquisition. A total of 130 adults participated in the study. Knowledge scores improved from pre to post-test. Individuals with low-literacy had less total knowledge score gains compared to individuals with marginal and adequate literacy. Researchers concluded that individuals with low-literacy may need additional instruction, repeated viewing, or additional tangible cues to support knowledge retention. Based on this recommendation the proposed study included a hand out to be given to caregivers after the educational intervention to provide additional reinforcement of information.

Providing appropriate learning material and adequate education may bring about desired changes in the behavior of learners. For example, a study investigated if different dietary interventions actually affect the behavior of patients (Fries et al., 2005). This randomized, controlled trial investigated the impact of a low–intensity, physician endorsed, self help dietary intervention. Seven hundred and fifty-four patients were surveyed to assess dietary information and then randomly assigned to an intervention or control group. The intervention group received a series of customized feedback, followed by brief telephone counseling, and theory-based nutritional education booklets delivered to their home. The control group received usual care which consisted only of education

but not feedback and follow up. Researchers discovered that the intervention group demonstrated significant improvement in dietary fat and fiber behaviors and intentions to change fat and fiber intake at 1, 6, and 12 month follow-ups. This study suggests that through adequate education, the health-related behavior of patients can be improved.

Above reviewed studies investigated how to provide education to illiterate or low-literacy populations using different techniques. All above studies reported were performed in the United States with one study focusing on a Hispanic population in the United States. There have been no studies conducted in Central America assessing information acquisition and information retention using a pictorial booklet.

The purpose of the booklet developed for the study, was to provide Central American nurses with a culturally appropriate, nutrition education tool to educate caregivers of pediatric oncology patients about food safety. It will be distributed as a resource for caregivers during treatment and after treatment in the home. The goal of this low-literacy, nutrition education tool is to emphasize to the caregivers a more cautious approach to bringing food into the hospital and preparing meals for their children at home.

Chapter 3

METHODOLOGY

Overview of the Study

Patients undergoing anticancer therapy, including chemotherapy, are at a higher risk of acquiring foodborne illnesses, particularly those of infectious etiology. To address the lack of culturally appropriate food-safety educational materials for caregivers of cancer patients, an eight-page, color-illustrated educational intervention tool called "Alimentación del niño con cáncer (Nutrition for the child with cancer)" was developed. This *Alimentación* booklet addresses specific steps to follow for food safety. It was designed for the low-literacy levels of many caregivers of pediatric oncology patients in Guatemala and El Salvador.

The purpose of the study had 3 parts:

1. Test efficacy of the *Alimentación* booklet as an educational intervention for low-literacy population. Use a pre- and post-test to determine information acquisition and information retention.

2. Determine storage and cooking facilities and water supplies available to this population.

3. Identify which variables affect pre intervention knowledge, information retention and information acquisition in the study population.

The long-term goal of this study is to decrease foodborne illnesses in this population and thus improve treatment outcomes. However, the long-term goal was not tested as a part of this study.

Institutional Review Board

Approvals of the Institutional Review Boards (IRB) were obtained from St Jude Children's Research Hospital (SJCRH), Universidad Francisco Marroquin, Guatemala City, Guatemala, and Hospital Nacional de Niňos Benjamin Bloom in San Salvador, El Salvador and at The University of Memphis, Memphis, U.S.A.

Verbal informed consent was obtained from each participant by nurse educator from each country. It was stated by the Institutional Review Board at SJCRH that this study poses no harm to the participants and can bring only benefits to the participants by increasing their knowledge about food safety. They suggested that the agreement to participate in the study will be accepted as a verbal consent to participate. The investigator explained details and the purpose of the study to the caregiver. Then, the investigator asked the caregiver, if she/he wanted to participate in the study; if the caregiver agreed to participate, she/he was signed up for the study.

Site Selection

Justification

Both hospitals (Unidad Nacional de Oncología Pediátrica in Guatemala City and Hospital Nacional de Niňos Benjamin Bloom in El Salvador) requested development of an educational handout for teaching of low-literacy caregivers about food safety. There was no educational material available to teach caregivers about food safety. Lack of educational material was identified as the main reason why a food safety guidelines are not followed resulting in a high incidence of foodborne infections in the hospitals.

Feasibility

The sites were selected by the Asociacion de Hemato-Oncologia Pediatrica de Centro America (AHOPCA) consortium. The selected locations were Unidad Nacional de Oncología Pediátrica in Guatemala City and Hospital Nacional de Niňos Benjamin Bloom in El Salvador. Both hospitals are the main centers for treatment of pediatric oncology patients in the relevant country. Both centers are supported by the local foundations that raise money for their maintenance and by the SJCRH.

These two sites were selected because SJCRH cooperates with those hospitals and has established International Outreach Program (IOP) for nurses in those hospitals. Nurse educators, who have been selected and trained to work on this research, are participants of the IOP for nurses.

Population and Sample

Participants were caregivers of children undergoing a treatment for Acute Lymphoblastic Leukemia (ALL) in two public hospitals, one in El Salvador and one in Guatemala City. Most of those caregivers have low-literacy levels or are illiterate. In the year 2002 in Guatemala, 31% of the total population was illiterate and 25% of all adult males were illiterate. In 2007 in El Salvador, 19% of the total population was illiterate. Male illiteracy was 17%. The definition of literacy states that a 15-year-old person is able to read and write (NationMaster, 2010). Unfortunately female literacy was not reported in this source. Low literacy or a limited literacy is defined as an inability to read or write well enough to perform necessary tasks in the society or on the job. There are no available statistics regarding low-literacy levels in El Salvador or Guatemala. In the U.S.A, low-literacy is generally categorized as having a reading level at or below the

forth grade. "Low-literacy materials" are written in a simple language and can be understood by people with limited literacy skills (Mc Kinney & Kurtz-Rossi, 2000). Average years of schooling are 3.5 years per adult in Guatemala and 5.2 years per adult in El Salvador (NationMaster, 2010). Since few reach 7th grade it is reasonable to conclude that the majority of the population in both countries have a low literacy level.

The study included all caregivers who have a child newly diagnosed with ALL and this child has started a treatment in either hospital: Unidad Nacional de Oncología Pediátrica in Guatemala City or in the Hospital Nacional de Niňos Benjamin Bloom in San Salvador. There is a socio-economic difference in caregivers between those two hospitals. In Guatemala, the majority of patients from the high-income level class are treated in private hospitals and clinics, while patients whose caregivers can not afford to pay for a private hospital are treated in a public hospital like the Unidad Nacional de Oncología Pediátrica, in which the study was conducted. In El Salvador, no private clinics specialize in pediatric oncology and all patients are treated in the Hospital Nacional de Niňos Benjamin Bloom, where this study was conducted. Therefore, a mixture of high- and low-income class caregivers and, probably, also a mixture of high- and low-literacy levels in El Salvador can be expected.

Caregiver Selection and Criteria

All families with a newly diagnosed child with leukemia were invited to participate in the study (Unidad Nacional de Oncología Pediátrica in Guatemala City or in Hospital Nacional de Niňos Benjamin Bloom in San Salvador). The pilot study dealt with the first 26 caregivers in either country who agreed to participate. For the main

study, all caregivers with newly diagnosed children with ALL during the time period between March 2008 and February 2010 were invited to participate.

Participation in the study was voluntary. It was explained to caregivers that participating in the study is voluntary and declining to participate will not affect treatment of their child.

Research Team

Nurse Educator's Background

A nurse educator is a nurse who coordinates educational activities of other nurses in the hospital. In both hospitals, the Nursing Program of IOP has a nurse educator who is responsible for educating nurses in her/his hospital. Only one nurse educator exists in each hospital. The nurse educators travel to Chile or SJCRH to receive training. Then, in their home hospitals, they train other nurses in skills such as how to administer chemotherapy, central-line care, food safety and importance of hand washing. Nurse educators were identified by the director of the Nursing Program in IOP of the SJCRH and by the administrative board of the local hospital. The selection was based on the level of experience in pediatric oncology nursing, education and availability. The nurse educator's salary is partially paid by the IOP of the SJCRH and partially by the local hospital.

Nurse Educators in this Study

The nurse educators collected data using three instruments, a demographic questionnaire, a pre-test and a post-test. In addition the nurse educator provided educational intervention using the *Alimentación* booklet. One male nurse educator from Guatemala and one female nurse educator form El Salvador collected data. In the middle

of the study, a dietitian from Guatemala was trained to collect data in the Guatemala hospital.

The activities performed by the nurse educators were:

1. Explain the study to caregivers
2. Obtain verbal consent of caregivers
3. Collect data using pre-test instrument
4. Provide educational intervention using low-literacy booklet *Alimentación*
5. Collect data using post-test instrument
6. Collect data using pre-test instrument after 1 month
7. Provide re-education intervention using low-literacy booklet *Alimentación*
8. Collect data using post-test instrument after 1 month
9. Collect data using post-test instrument after 3 months
10. Collect data using demographic questionnaire instrument

Educational Intervention (see Appendix A: *Alimentación* Booklet)

Treatment is defined as a care provided and remedies administered or applied to a patient to improve patient's health situation deteriorated by a disease. In this study, treatment is educational intervention provided to caregivers using *Alimentación* booklet.

Alimentación Booklet (educational intervention)

The *Alimentación* booklet was developed in five stages:

Stage 1. Identification of the problem was described earlier in the introduction and was presented at the AHOPCA (2007) meeting in the Dominican Republic in 2007 (Mosby et al., 2008).

Stage 2. The survey for nurses was developed and administered in three Central American hospitals. The purpose of the survey was to identify the needs of the hospitals for a nutritional educational handout and to identify common eating habits, so that culturally relevant education could be developed.

The topics covered by the survey, written in Spanish, included: 1) availability of educational materials; 2) need for a nutritional education handout; 3) input from a bedside nurse regarding the content of the handout; 4) foods commonly brought into the hospital by caregivers; 5) foods commonly consumed by the patients and their families; 6) caregiver's ability to read and comprehend written materials; 7) current hospital policy regarding the ingression of foods; 8) current strategies in place to deter ingression of unsafe foods; and 9) special ethnic or religious circumstances that affect patients' diets. This survey of nurses was validated and revised according to recommendations of a panel of experts. The survey was sent via email to nurses at hospital-based pediatric oncology units at three Central American hospitals: Hospital Escuela Bloque Materno Infantil, Tegucigalpa, Honduras; Unidad Nacional de Oncología Pediátrica, Guatemala City, Guatemala; and Hospital de Niños Benjamín Bloom, San Salvador, El Salvador.

Nurses' Survey Results

All surveyed nurses stated that their respective hospitals did not have any type of nutritional education materials available for caregivers of pediatric oncology patients. Mostly, nutritional education is offered through informal talks with the caregivers. All nurses expressed that an educational handout would be welcome and useful. They suggested the following topics for inclusion in the handout: nutrient-rich foods, general food safety, basic diet guidelines, nutrient content of foods, and prevention of food

contamination. The nurses also emphasized the importance of including the local foods in the handout to enhance relevancy and effectiveness of the handout. The estimated percentage of caregivers that could read at any of the given hospitals ranged from 60% to 85%; however, a level of reading capability was not specified. It was also mentioned that because most caregivers are unaccustomed to reading, they usually dislike doing so. To ensure that the majority of caregivers receive and understand the nutritional information, the handout needs to be designed for low-literate or illiterate populations.

Nurses reported that foods commonly brought into the hospital by the caregivers included tortillas, fast food, soup, candy, juice and other beverages, fruit, vegetables, salad, *elotes* (roasted or boiled ears of corn, smeared with butter or mayonnaise and topped with cheese, salt, lime juice, and chili powder), and *pupusas* (thick corn tortillas filled with cheese, beans, or meat). Common items consumed by the patients and their families included beans, tortillas, eggs, cereal, bread, rice, pasta, meat, seafood, soup, vegetables (greens, potatoes, carrots), fruit (bananas, oranges), pancakes, fast food, cheese, *pupusas*, juice, milk, and coffee. To ensure that the handout was culturally relevant, the majority of these foods were included.

Hospital policy regarding food brought in by caregivers varied from hospital to hospital. Two hospitals allow the ingression of homemade foods in special circumstances and with authorization from the nutrition department or the physician. The third hospital does not allow the ingression of foods from the home or bought on the street. Nevertheless, all nurses stated that the ingression of foods bought on the street or made by caregivers is a common practice at their hospitals. When it is discovered that a caregiver has brought food to the hospital without permission, he or she is verbally

instructed about the health risks and consequences of food poisoning and infection for the patient. Because the nurses divulged that caregivers often bring outside foods into the hospital, it is essential that caregivers and nurses alike be educated about benefits of a low-bacteria diet. If ingestion of potentially dangerous bacteria by the immuno-compromised patients is minimized, the risk of infections will be reduced (Todd et al., 1999).

Additional areas of concern of the nurses arose from ethnic and religious circumstances that affected the patients' diets. Religious beliefs that require a vegetarian diet were discussed by the nurses and professionals developing the *Alimentación* booklet. Example of religious beliefs was that one indigenous group does not eat meat. Nurses discussed with hospital workers the need to accommodate food safety recommendations based on dietary preferences that do not include meat. Additionally, the majority of nurses cited economic hardship in their responses, as well as a discrepancy between foods offered to in-patients versus foods commonly consumed in the patients' homes. By economic hardship nurses meant that some families have no finances or ways to provide special food for a patient, therefore, any restrictions of patient's diet make their situation even more complicated. An effort was made to include foods that both vegetarians and persons from lower socioeconomic classes typically consume.

Stage 3**.** Developmental stage. Findings from the nursing survey and other research were used in the developmental stage of *Alimentación* booklet which resulted in a 32-slide PowerPoint presentation that incorporated the text and images that were to be included in the *Alimentación* booklet. The PowerPoint presentation was submitted to the Biomedical Communications (BMC) Department that is responsible for designing,

copying, and printing of educational materials in the St. Jude Children's Research Hospital. Then, a BMC graphic artist used the PowerPoint presentation to generate an overall design of the *Alimentación* booklet. Several revisions were required to create a culturally sensitive nutritional handout for a low-literate population.

Stage 4**.** Content Validity Assessment (see Appendix E). Content validity assessment means determination of the content representativeness or content relevance of elements of an instrument (Lynn, 1986). It is a two-stage process that requires validation in the developmental and judgment-quantification stages (Lynn, 1986).

Content validity during the judgment-quantification stage requires the assertion by experts that the items' content is valid and that the entire instrument is valid (Lynn, 1986). Six experts can provide an adequate level of control for chance agreement (Lynn, 1986). Relevant training, experience, and qualifications of the selected panel of experts are essential (*Standards for educational and psychological testing*, 1985). Clinical expertise is also considered (Grant & Davis, 1997). Selection of experts from various geographic locations is important to increase the chance of detecting colloquial terms inappropriate for the instrument (Grant, Kinney, & Guzzetta, 1990). Item content, item style, and comprehensiveness are assessed using a rating scale (Grant & Davis, 1997). Results are quantified by application of the content validity index (CVI). CVI is the percentage of total items judged to be content-valid by receiving a score of 3 or 4 (Lynn, 1986). A new instrument should have a CVI of 80 % or above (Davis, 1992). A 4-point rating scale is advantageous, because it does not include the ambivalent middle rating present in odd-numbered scales (1 = not representative; 2 = in need of major revisions to

be representative; 3 = in need of minor revisions to be representative; 4 = representative) (Lynn, 1986).

Validation of the *Alimentación* booklet was provided by a panel of experts with expertise in patient education materials, low-literacy education, and nutrition. The panel validated both the accuracy of the information presented and cultural sensitivity. Subsequently, a Spanish-language 10-item content validity scale was developed. The handout was presented to nurses from El Salvador and Guatemala via a Horizon Live presentation on the Cure4Kids website (www.cure4kids.org). Cure4Kids is a web site which supports the care of children with cancer and other diseases worldwide. It also provides web communication tools to support collaborations among health professionals worldwide. The nurses were solicited for general comments and suggestions.

The nurses rated the following statements: 1) the booklet provides good recommendations about food safety for children diagnosed with cancer; 2) the booklet will be helpful for families of all ethnic, religious, and economic groups represented in your hospital; 3) foods are representative of those available to parents/caregivers; 4) foods are typical of those commonly consumed by families; 5) recommendations are presented in a clear manner; 6) parents/caregivers are likely to understand the content presented in the handout; 7) parents/caregivers will be more informed about what are the foods they can give to their children; 8) parents/caregivers will be more informed about what foods they should not give to their children; 9) recommendations are feasible for parents/caregivers to follow; and 10) statement, if they would use this booklet to educate parents/caregivers about the nutrition of their child with cancer.

Additionally, two questions regarding missing or superfluous information were included. Space for additional comments was available for each item. Upon completion, the scale was distributed to two nursing experts in Honduras, El Salvador and Guatemala. A cover letter stating why the individual was chosen, general information on the elements he/she will be addressing, and the significance of their participation in validating the instrument accompanied the survey (see Appendix E).

All six surveys were completed and returned. Based on the evaluation, the Content Validity Index (CVI) score for the booklet was 0.95.

Stage 5. The proposed content and objectives for the *Alimentación* booklet were reviewed by a panel of experts in the St. Jude Children's Research Hospital. Based on their suggestions, especially in wording, the content of the booklet was finalized. The booklet is geared toward the illiterate and low-literate population and features general food safety guidelines, examples of foods that can be safely consumed by patients and foods that should be avoided.

Nurse Educators'Ttalk (see Appendix B)

A nurse educators' talk was developed to maintain consistency in the educational intervention of caregivers using *Alimentación* booklet. One nurse educator collected data in El Salvador because dietitians were not available to assist. In Guatemala a dietitian and a nurse educator shared the responsibility of collecting data. The dietitian joined the study immediately after the pilot study was completed. Therefore one nurse educator from El Salvador and one nurse educator and one dietitian from Guatemala were trained to explain this study to a caregiver and to obtain his or her verbal consent to participate in the study, administer the pre-test, provide education intervention about food safety using

the *Alimentación* booklet, administer post-test, and re-administer pre-test, provide re-education intervention and administer post-test after one month and post-test after 3 months. The dietitian was added in Guatemala location because the nurse educator was too busy with other assignments and did not have time to educate all eligible caregivers.

Instruments

Pre- andPost-test Questionnaire (see Appendix C)

The pre- and post-tests are identical. The pre- and post-test questionnaire for caregivers was developed and validated to assess knowledge of food safety prior to receiving the education intervention using *Alimentación* booklet and after receiving the education intervention. The test was validated by a group of experts using CVI. The CVI for the test was 0.95 (see Appendix E).

The pre- and post-test questionnaire consists of 10 questions (Appendix C). Each question was designed to investigate whether the caregiver correctly understands one topic taught by the *Alimentación* booklet and expressed by a picture. Four multiple choice answers for each question were designed to incorporate the most common mistakes that are usually made for each topic taught. Only one answer is correct for each question. The questions deal with the following topics:

1. general knowledge, if children with cancer have any dietary restrictions
2. leftovers and eating out
3. safe food preparation
4. safe cooking methods
5. appropriate drinks
6. fruits child can have

7. what vegetables child can have
8. foods which are restricted
9. restricted foods
10. foods allowed

Demographic Questionnaire (see Appendix D)

A demographic questionnaire was developed to gather information about caregivers and about food preparation, water supply and food storage to better focus and target future education. Variables in demographic questionnaire were: relationship of caregiver to patient (mother, father, other), a nominal (categorical) variable; gender of caregiver (male, female), a nominal (categorical) variable; age of caregiver (exact number), an interval variable; number of persons living in the same house as patient (1 to 10+), an interval variable; caregiver being the same person that usually prepares meals for patient (yes, no), a nominal variable; person who usually prepares meals for patient (mother, father, grandmother, grandfather, other), a nominal variable; possession of an electric or gas stove (yes, no), a nominal variable; refrigerator (yes, no), a nominal variable; microwave (yes, no), a nominal variable; source of drinking water (municipal water, well, bottle water, other), a nominal variable; ability to read (yes, no), a nominal variable; and monthly income per family (exact number), an interval variable.

Data Definition

Independent variables are country, gender of caregiver, age of caregiver; self-reported ability to read, economical level (owning stove, refrigerator or microwave), number of family members living in the same house as the patient, responsibility for food

preparation for the patient, relationship to the patient, source of water used and self reported literacy.

The workflow diagram was as follow: after patient's diagnosis was confirmed caregiver was invited to participate in the study. First pre-test1 was administered, then caregiver was educated and immediately after education a post test1 was administered. One month later pre-test2 was administered; caregiver was reeducated and immediately after education post test2 was administered. Two month later (3 month post 1st education) a posttest3 was administered.

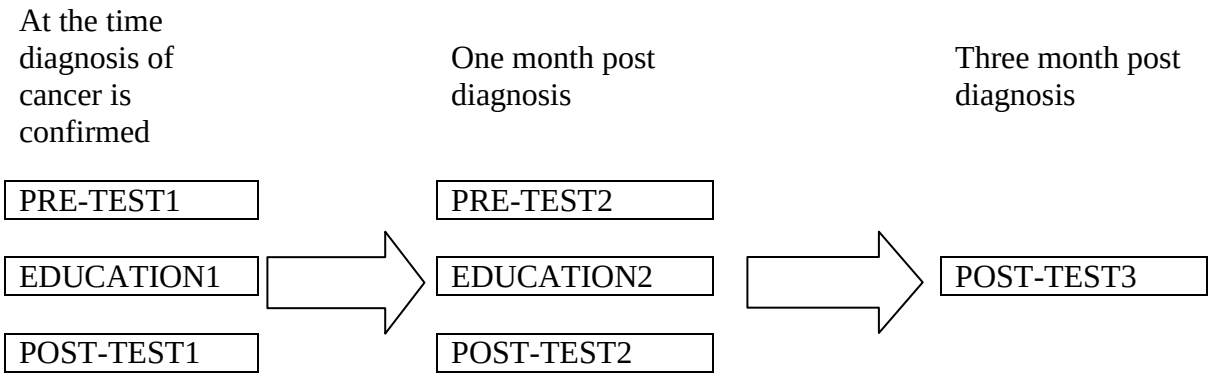


Figure 1. Steps in the Research Process

The study was designed to test the acquisition and retention of knowledge. Acquisition of knowledge was measured comparing results from post-test1 with results from pre-test1. Retention of knowledge at one month was measured by comparing results from pre-test2 with post-test1. Retention of knowledge at 3 months was measured by comparing results from post-test3 with post-test1. Terminology of pre- and post-test corresponds to timing of the tests before and after education, respectively. Regarding

content of the tests, pre- and post-tests are identical. The pre- and post-test questionnaires contain ten multiple choice questions, each has only one correct answer.

Dependent variables are pre-educational intervention knowledge about food safety (pre-test1), acquisition of information after educational intervention (post-test1), and retention of information (pre-test2 and post-test3). Information acquisition was measured by comparing right answers before educational intervention and right answers after educational intervention. Information retention was measured by comparing right answers in post-test at three points in time 1) right after education, 2) after one month, 3) after three months.

One constructed variable was developed:

Socioeconomic status

0: no stove, no refrigerator, no microwave

1: one of the following: stove, refrigerator or microwave

2: two of the following: stove, refrigerator or microwave

3: all three items owned

Socioeconomic status = 0 means the lowest socioeconomic status

Socioeconomic status = 3 means the highest socioeconomic status

Data Collection

The researcher trained the nurse educators and the dietitian. Training was provided in person during the 2008 AHOPCA meeting in Honduras and also using a two-way, web-based classroom, which is a part of the cure4kids website. Reeducation in person was provided at AHOPCA 2009 in Costa Rica. The dietitian from Guatemala was trained in person during her visit to SJCRH in 2009. Nurse educators learned how to

explain the study to a caregiver, obtain verbal consent, administer a demographic questionnaire, administer pre-test1, provide education1 intervention about food safety using the *Alimentación* booklet, administer post-test1 immediately after education intervention, administer the pre-test2 and post-test2 and administer post-test3. The post-test3 was evaluated only in a limited number of caregivers in the pilot study because it showed no difference in knowledge retention. Based on the results of the pilot study, there was very little difference between the post test at one month and post test at three months. Information retention remained at or near the same level. Therefore, the post test at three months was dropped.

Six types of data were collected;

1. Demographic data obtained using Demographic Questionnaire instrument and completed by 162 caregivers (126 caregivers in El Salvador and 36 caregivers in Guatemala). The pilot study used the same educational intervention involving the *Alimentación* booklet and pre/post-tests. Therefore, the pilot study data from 26 caregivers were included in the main study in order to increase the number of cases. Total of 162 questionnaires were evaluated. Information on the following variables was collected in the study: country, gender and age of caregiver, relation to patient, self-reported ability to read, socio-economical level (owning stove, refrigerator or microwave), number of family members living in the same house as the patient, responsibility for food preparation for the patient, and source of water used.

2. Pre-test1 evaluating caregiver's knowledge about food safety prior to education intervention using *Alimentación* booklet.

3. Post-test1 evaluating caregiver's knowledge about food safety immediately following education1 intervention with *Alimentación* booklet.

4. Pre-test2 one month following the initial education1 intervention with *Alimentación* booklet.

5. Post-test2 immediately following re-education2 intervention provided one month following the initial education1 intervention with *Alimentación* booklet.

6. Post-test3 three months after initial education1 intervention.

All information from Guatemala was collected by a trained nurse educator, and a trained dietitian. Hard copies of pre- and post-tests and demographic questionnaires from the Guatemala site were delivered to the researcher during the AHOPCA meeting in February 2010.

All information from El Salvador was collected by a trained nurse educator. Hard copies of the demographic questionnaires and pre- and post-tests were picked up by the researcher in November 2010 in El Salvador when the researcher visited the hospital.

Research Questions

The following questions and descriptions were developed to address the 3 part purpose of the study. The method of testing and analysis is also listed for each question.

1. Test efficacy of *Alimentación* booklet, as an educational intervention for low literacy population. Use a pre- and post-test to determine information acquisition and information retention.

    a. Does knowledge of food safety improve after the first educational intervention?

        Compare correct answers in pre-test1 and post-test1

Wilcoxon Signed Ranks test

b. Is knowledge retained one month after first educational intervention?

Compare correct answers in post-test1 and pre-test2

Wilcoxon Signed Ranks test

c. Is learning acquisition different in Guatemala and in El Salvador?

Compare results from post-tests1

Descriptive statistic (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*)

Wilcoxon Signed Ranks test

2. Determine available food storage, cooking facilities, and water supply available to the caregivers

a. Describe food storage facilities

Frequency distribution (%)

b. Compare Guatemala and El Salvador storage facilities

Frequency distribution (%)

3. Identify which variables affect information retention and information acquisition in the caregivers

a. Is knowledge retained three months after first educational intervention?

Compare correct answers in post-test1 and post-test3

Wilcoxon Signed Ranks test

b. Does information acquisition depend on caregiver's relationship to patient?

Generalized Cochran –Mantel-Haenszel Test

c. Does information acquisition depend on caregiver's gender?

   Generalized Cochran –Mantel-Haenszel Test

d. Does information acquisition depend on age of caregiver?

   Generalized Cochran –Mantel-Haenszel Test

e. Does information acquisition depend on how many people live in household?

   Generalized Cochran –Mantel-Haenszel Test

f. Does information acquisition depend on a caregiver being also the main cook

   Generalized Cochran –Mantel-Haenszel Test

g. Is there a difference in information acquisition between self reported illiterate and literate caregivers?

   Generalized Cochran –Mantel-Haenszel Test

h. Does information acquisition depend on socioeconomic status?

   Use four categories

   Generalized Cochran –Mantel-Haenszel Test

i. Describe post-test3 scores

   Descriptive statistics (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*)

j. Compare scores of post-test1, post-test2 and post-test3

   Wilcoxon Signed Ranks test

4. Examine pre-education knowledge and variables which may affect pre-educational knowledge

a. Is there a difference in pre-educational intervention knowledge in Guatemala and in El Salvador?

   Pre-educational intervention knowledge is the pre-test1

   Wilcoxon Signed Ranks test

   Descriptive statistic (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*)

b. Does pre-educational intervention knowledge depend on gender?

   Pre-intervention knowledge is the pre-test1

   Wilcoxon Mann-Whitney Test

c. Does pre-educational intervention knowledge depend on how caregiver is related to patient?

   Kruskal Wallis Test

d. Does pre-educational intervention knowledge depend on age of caregiver?

   Spearman's rank correlation, $p < 0.05$ was chosen as the nominal significance level.

e. Does pre-educational intervention knowledge depend on how many people are living in the household?

   Spearman's rank correlation, $p < 0.05$ was chosen as the nominal significance level.

f. Does pre-educational intervention knowledge depend on a caregiver being also the main cook in the family?

   Kruskal Wallis

g. Does pre-educational intervention knowledge depend on literacy (self-reported)?

   Wilcoxon Mann-Whitney Test

h. Does pre-educational intervention knowledge depend on caregiver owning a stove?

   Wilcoxon Mann-Whitney Test

i. Does pre-educational intervention knowledge depend on caregiver owning a microwave?

   Wilcoxon Mann-Whitney Test

j. Does pre-educational intervention knowledge depend on caregiver owning a refrigerator?

   Wilcoxon Mann-Whitney Test

k. Does pre-educational intervention knowledge depend on the source of water family is using?

   Kruskal Wallis Test

l. Does pre-educational intervention knowledge depend on the family's income?

   Spearman's rank correlation, $p < 0.05$ was chosen as the nominal significance level.

m. Does pre-educational intervention knowledge depend on how many people are supported by the family income?

   Spearman's rank correlation, $p < 0.05$ was chosen as the nominal significance level.

n. Does pre-educational intervention knowledge depend on socioeconomic status?

Four categories were used:

0: no stove, no refrigerator, no microwave

1: one of the following: stove, refrigerator or microwave

2: two of the following: stove, refrigerator or microwave

3: all three items owned

Socioeconomic status = 0 means the lowest socioeconomic status

Socioeconomic status = 3 means the highest socioeconomic status

Wilcoxon Mann-Whitney Test

Additional Question:

5. Comparing results between countries

a. Compare Guatemala and El Salvador by socioeconomic status using four categories explained above.

Frequency distribution

Wilcoxon Mann-Whitney Test

b. Compare caregivers from El Salvador and Guatemala by age of caregiver, number of people living in the house, family income, how many people are supported from the income (continuous variables).

Descriptive statistics (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*)

c. Compare caregivers from El Salvador and Guatemala by relationship to patient, gender of caregiver, gender of patient, being the one who cooks

for patient, by who is the main cook in the family, having stove, refrigerator and microwave.

Frequency (%) distribution.

d. Is there a difference in information retention between caregivers from Guatemala and caregivers from El Salvador? Compare pre-test1 scores, post-test1 scores and post-test2 scores by country

Descriptive statistics (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*).

e. Determine whether there was a difference in pre-educational intervention knowledge between caregivers in Guatemala and caregivers in El Salvador

Wilcoxon Mann-Whitney Test

f. Determine whether there was a difference in information acquisition between caregivers in Guatemala and caregivers in El Salvador

Generalized Cochran –Mantel-Haenszel Test

Missing data:

If a caregiver did not provide answers to five or more questions in one test or questionnaire, none of their responses from the tests or questionnaire were included in the study.

Tests Used for Data Analysis

Wilcoxon signed-rank test is a non-parametric statistical hypothesis test for two related samples or repeated measurements on a single sample. It can be used as an alternative to the paired Student's t-test when the population cannot be assumed to be

normally distributed. Examples are comparing scores of pre-test1 and post-test1; pre-test1 and post-test2 and post-test1 and post-test2.

The Wilcoxon Mann-Whitney Test is a non-parametric statistical hypothesis test for assessing whether two independent samples of observations have equally large values. Mann Whitney test is similar to 2 levels *ANOVA* for independent samples. *P-value* of < *0.05* was chosen as the nominal significance level. The Wilcoxon Mann-Whitney Test was applied to examine, if there was an association between pre-test scores and demographic variables that have two levels. Examples are gender and yes/no questions.

Kruskal–Wallis one-way analysis of variance by ranks is a non-parametric method for testing equality of population medians among groups. It is identical to a one-way analysis of variance (*ANOVA*) with the data replaced by their ranks. It is an extension of the Wilcoxon Mann-Whitney Test to three or more groups. The Kruskal Wallis test was conducted to test if pre-test scores were associated with demographic variables which have more than two levels. Examples are questions: relationship to patient, who is the main cook in the family, what water source are you using.

Spearman's rank correlation coefficient is a non-parametric measure of statistical dependence between two variables. It assesses the association between two variables. Pearson correlation can be used to see the relationship between two normally distributed variables. If one or both of the variables are not normally distributed, nonparametric method, Spearman correlation can be used. In the analysis, the normality assumption was not satisfied, so Spearman correlation was applied. The Spearman's rank correlation coefficient was used to detect the relationship between pre-test scores and continuous

demographic variables (age of caregiver, number of people living in the house, family income, how many people are supported from this income). A *p-value* of < 0.05 was chosen as the nominal significance level.

Generalized Cochran-Mantel-Haenszel Test gives a stratified statistical analysis of the relationship between C and D, after controlling for A and B strata. The stratified analysis provides a way to adjust for the possible confounding effects of A and B without being forced to estimate parameters for them. The generalized Cochran-Mantel-Haenszel Test was used to examine if there was an association between learning ability and demographic variables. Pre-test scores were used for adjustment. A *p-value* of < 0.05 was chosen as the nominal significance level.

Frequency distribution (in percent) was used for description of the sample.

Descriptive statistics (*N, Min, 5th percentile, median, 95th percentile, Max, Mean, Standard deviation*) was used.

p-values tell us whether an effect can be regarded as statistically significant or not. If a study is done to compare two treatments then the P value is the probability of obtaining the results of that study. The assumption that there is no difference between treatments is called the 'null hypothesis'. If a *p-value* is $p = 0.05$, this means that if there really was no difference between treatments then there would only be a 5% chance of getting the result obtained. Since this chance seems quite low, it could probably be concluded that there probably is a difference between treatments. Usually, where the *p* -

value is below 0.05 (i.e. less than 5%) the result is seen as statistically significant. Where the value of *p-value* is 0.001 or less, the result is seen as highly significant.

SAS version 9.2 was used for statistical analysis.

Chapter 4

DATA ANALYSIS

Main Study

Participants

A total of 162 caregivers of newly diagnosed pediatric patients with Acute Lymphoblastic Leukemia (ALL) from two public hospitals in El Salvador and Guatemala were invited to participate in the study. Most of the time, the patient was brought into the hospital accompanied by the mother, 75% in El Salvador and 72% in Guatemala. The father brought the patient to the hospital 14% of the time in El Salvador and 19% of the time in Guatemala. Other persons who brought the patient to the hospital included sister, aunt, uncle or other relative. They brought a patient to the hospital 10% of the time in El Salvador and 9% of the time in Guatemala. The mean age of a caregiver in El Salvador was 32.65 years (*SD* ± 8.91) and 34.18 years (*SD* ± 9.68) in Guatemala. The mean number of people living in the same household as patient was 5.2 (*SD* ± 2.15) in El Salvador and 5.6 (*SD* ± 2.0) in Guatemala. There were no significant differences between countries regarding the demographic data described above. The caregivers had low literacy levels or were illiterate.

Demographic Questionnaire

Demographic questionnaires were completed by 162 participants of this study. Frequency distribution for demographic variables by country is shown in the Table 2. Descriptive Statistics for continuous demographic variables by country is summarized in the Table 3.

Table 2

Frequency Distribution of Demographic Variables by Country

Variables	El Salvador Frequency (%)	Guatemala Frequency (%)	Total Frequency (%)
Relationship to patient			
n/a	1 (0.79)	0 (0.00)	1(0.62)
Mother	95 (75.40)	26 (72.22)	121 (74.69)
Father	18 (14.29)	7 (19.44)	25 (15.43)
Other	12 (9.52)	3 (8.33)	15 (9.26)
Gender of caregiver			
n/a	1 (0.79)	13 (36.11)	14 (8.64)
Female	105 (83.33)	16 (44.44)	121 (74.69)
Male	20 (15.87)	7 (19.44)	27 (16.67)
Are you the one who cooks for patient?			
Yes	98 (77.78)	25 (69.44)	123 (75.93)
No	28 (22.22)	11 (30.56)	39 (24.07)

Table continues

Table 2 (continued)

Frequency Distribution of Demographic Variables by Country

Variables	El Salvador Frequency (%)	Guatemala Frequency (%)	Total Frequency (%)
Who is the main cook in the family?			
n/a	0 (0.00)	1 (2.78)	1 (0.62)
Mother	100 (79.37)	31 (86.11)	131 (80.86)
Father	1 (0.79)	0 (0.00)	1 (0.62)
Grand m.	8 (6.35)	4 (11.11)	12 (7.41)
other	17 (13.49)	0 (0.00)	17 (10.49)
Do you have stove?			
Yes	105 (83.33)	22 (61.11)	127 (78.40)
No	21 (16.67)	14 (38.89)	35 (21.60)
Do you have refrigerator?			
n/a	2 (1.59)	0 (0.00)	2 (1.23)
Yes	88 (69.84)	18 (50.00)	106 (65.43)
No	36 (28.57)	18 (50.00)	54 (33.33)
Do you have microwave?			
n/a	3 (2.38)	0 (0.00)	3 (1.85)
Yes	29 (23.02)	11 (30.56)	40 (24.69)
No	94 (74.60)	25 (69.44)	119 (73.46)

Table continues

Table 2 (continued)

Frequency Distribution of Demographic Variables by Country

Variables	El Salvador Frequency (%)	Guatemala Frequency (%)	Total Frequency (%)
What water source are you using?			
n/a	1 (0.79)	0 (0.00)	1 (0.62)
Municip. w.*	8 (6.35)	12 (33.33)	20 (12.35)
Well water	12 (9.52)	11 (30.56)	23 (14.20)
Bottled water	26 (20.63)	3 (8.33)	29 (17.90)
Other	20 (15.87)	10 (27.78)	30 (18.52)
Tap water**	59 (46.83)	0 (0.00)	59 (36.42)
Can you read? (self-reported)			
n/a	1 (0.79)	0 (0.00)	1 (0.62)
Yes	113 (89.68)	31 (86.11)	144 (88.89)
No	12 (9.52)	5 (13.89)	17 (10.49)
Total number of caregivers	126	36	162

n/a = data are missing

* Municipal water is brought to a location in large tanks and carried to local houses in containers.

** Tap water is water coming from the faucet.

Table 3

Descriptive Statistics for Demographic Variables (continuous) by Country

	Variable	*N*	Min correct	Median	Max correct	Mean correct	Std Dev
El Salvador	Pre-test1 score	113	1	6	9	6.10	1.77
	Post-test1 score	114	8	10	10	9.94	0.28
	Post-test2 at 1month score	75	8	10	10	9.88	0.37
Guatemala	Pre-test1 score	36	3	7	10	6.71	1.76
	Post-test1 score	35	3	9	10	8.47	1.52
	Post-test2 at 1month score	12	6	9	10	9.08	1.16

Table 4 is showing scores of pre-test1, post-test1and post-test2 at one month after first educational intervention (Table 4).

Table 4

Descriptive Statistics for Pre-test1score/ Post-test1 score/ Post-test2 at One Month by Country

	Variable	*N*	Min.	Median	Max.	Mean	SD
El Salvador	Age of caregiver	125	18	31	70	32.65	8.91
	Number of people living in the house	126	2	5	17	5.21	2.15
Guatemala	Age of caregiver	22	19	33	53	34.18	9.68
	Number of people living in the house	36	3	5	11	5.61	2.00

Table 5 is showing comparison of scores of pre-test1 and post-test1 / pre-test1 and post-test2 at one month/ post- test1 and post-test2 at one month (Table 5). Wilcoxon Signed Ranks test was used for each comparison. There was significant difference in test scores between pre-test1 and post-test1, pre-test1 and post-test2 at one month in each country (*p-values* < 0.01). Post-test1 scores did not significantly differ from post-test2 at one month either in El Salvador (*p-value* = 0.0918) or in Guatemala (*p-value* = 0.0781).

Table 5

Information Acquisition and Retention

	El Salvador	Guatemala
Pre-test1 – Post-test1	<0.0001	<0.0001
Pre-test1 – Post-test2 at one month	<0.0001	0.0020
Post-test1 – Post-test2 at one month	0.0918	0.0781

Examination of relationship between pre-test1 score (pre - educational knowledge) and demographic information about caregivers is shown in table 6 (Table 6). Demographic variables were examined to determine if they were associated with pre-education knowledge about food safety. Wilcoxon Mann-Whitney Test was applied to examine the association between pre-test1 scores and demographic variables that had two class levels (for example gender). The Kruskal Wallis test was conducted if pre-test1 scores were associated with demographic variables that had more than two levels. Spearman's rank correlation was used to detect the relationship between pre-test1 scores and continuous demographic variables. All tests were performed separately for each country. Table 6 shows *p-values* from the statistical tests. A *p-value* greater than 0.05 indicates no significant relationship between pre-test score and demographic variable exists. There was no statistically significant relationship found.

Table 6

Relationship between Pre-test1 Score and Demographic Variables

	El Salvador (*p-values*)	Guatemala (*p-values*)
Wilcoxon-Mann-Whitney Test		
Gender of caregiver	0.4929	0.3435
Are you the one who cooks for patient?	0.6001	0.6653
Do you have stove?	1.0000	0.4085
Do you have refrigerator?	0.8957	0.5293
Do you have microwave?	0.3381	0.5458
Can you read?(self reported)	0.0145	0.4546
Kruskal-Wallis Test		
Relationship to patient	0.5936	0.3325
Who is the main cook in the family?	0.8681	0.6992
What water source are you using?	0.4860	0.6153
Spearman's Rank Correlation		
Age of caregiver	0.2958	0.8272
Number of people living in the house	0.2985	0.7996

Test scores on post-test3 at three months after education1 is shown in table 7 (Table 7). The majority of caregivers did not take the post-test3. Only eight caregivers in Guatemala did.

Table 7

Information Retention at 3 Month (Descriptive)

	Variable	N	Min	Median	Max	Mean	Std Dev
Guatemala	Post-test3 score	8	8.00	10.00	10	9.38	0.92

Comparison of scores of post-test1 and post-test3 and comparison of scores of post-test2 and post-test3 is shown in table 7. Only eight caregivers had records of post-test3, so the comparisons involved only those caregivers. Wilcoxon Signed Ranks test was used for each comparison. There was no significant difference in test scores between post-test1 and post-test3 (*p-value* = 0.3125). There was also no significant difference in test scores between post-test2 and post-test3 (*p-value* = 1.0000).

Determine whether there was a difference in pre-intervention education knowledge or information acquisition between caregivers in Guatemala and caregivers in El Salvador (Table 8). Table 8 shows descriptive statistics for change score by country. Change score refers to knowledge acquisition. It is the difference between post-test1score – pre-test1 score. There was no significant difference in pre-intervention knowledge between Guatemala and El Salvador (p-value = 0.1350). Information acquisition of caregivers in San Salvador significantly differed from that of caregivers in Guatemala City (p-value < 0.0001).

Table 8

Descriptive Statistics for a Change Score by Country

Country	Variable	N	Min	Median	Max	Mean	Std Dev
El Salvador	Change score	113	1.00	4.00	8.00	3.84	1.72
Guatemala	Change score	33	2.00	2.00	6.00	1.88	1.85

Examine whether there was a relationship between information acquisition and demographic variables about caregivers (Table 9). Generalized Cochran-Mantel-Haenszel Test was applied to examine the association between information acquisition and demographic variables. Table 9 shows p-values obtained by the statistical test. There was no significant association between information acquisition and demographic variables in each country (p-values > 0.05).

Table 9

Association between Information Acquisition and Demographic Variables

(p-values from Generalized Cochran-Mantel-Haenszel Test)

Variable	El Salvador *p-values*	Guatemala *p-values*
Gender of caregiver	0.1029	0.8181
Are you the one who cooks for patient?	0.2982	0.6035
Do you have stove?	0.6382	0.8604
Do you have refrigerator?	0.4994	0.2251
Do you have microwave?	1.0000	0.3145
Can you read?	1.0000	0.7990
Relationship to patient	0.1136	1.0000
Who is the main cook in the family?	0.8071	0.8292
What water source are you using?	0.5305	0.7473
Age of caregiver	0.7999	0.6652
Number of people living in the house	0.8199	0.0667
What is the family income?	1.0000	0.1227
How many people are supported from this income?	1.0000	0.8060
Socioeconomic status*	0.8571	0.3686

* Socioeconomic status is a variable involving caregiver's ownership of a stove, refrigerator or microwave.

0: no stove, no refrigerator, no microwave

1: one of the following: stove, refrigerator or microwave

2: two of the following: stove, refrigerator or microwave

3: all three items owned

Socioeconomic status = 0 means the lowest socioeconomic status

Socioeconomic status = 3 means the highest socioeconomic status

Comparison of socioeconomic status between caregivers in Guatemala and caregivers in El Salvador (Table 10). Table 9 shows frequency distribution for the socioeconomic status variable by country. Wilcoxon Mann-Whitney Test was used to examine the relationship between socioeconomic status and country. There was no significant difference in socioeconomic status between Guatemala and El Salvador found (p-value = 0.1866).

Table 10

Frequency Distribution for Socioeconomic Status by Country

Socioeconomic Status	El Salvador	Guatemala	Total
.	3 (2.38) *	0 (0.00)	3
0	19 (15.08)	14 (38.89)	33
1	17(13.49)	4 (11.11)	21
2	60 (47.62)	7(19.44)	67
3	27 (21.43)	11 (30.56)	38
Total number of caregivers	126	36	162

* Some caregivers did not report if they had refrigerator and microwave. Caregiver of one patient in El Salvador did not report if she had microwave.

Pre-test1 scores (pre educational knowledge) had no significant relationship with gender of caregiver, caregiver being the same person that cooked for the patient, having stove, having refrigerator, having microwave, relationship of caregiver to patient, being the person who usually cooked for patient, source of drinking water, age of caregiver, number of persons living in the same house as patient, monthly income per family, number of persons being supported from this income in each country (all *p-values* > 0.05).

Pre-test1 scores (pre educational knowledge) of caregivers in El Salvador correlated with the ability to read and there was evidence that El Salvador caregivers who had ability to read obtained higher pre-test1 scores than caregivers unable to read (two-sided *p-value* = 0.0145, one-sided *p-value* = 0.0073). However, for caregivers in

Guatemala, no significant relationship between pre-test1 score and ability to read was found (*p-value* = 0.4546). There is not sufficient data to explain the difference because ability to read was self reported.

Summary of the Results

1. Significant differences in scores between pre-test1 and post-test1, pre-test1 and post-test2 at one month were found.

2. There was no significant difference in scores between post-test1 and post-test2 at one month.

3. Pre-test1 scores were not significantly associated with gender of caregiver, caregiver being the same person that cooked for patient, having stove, having refrigerator, having microwave, relationship of caregiver to patients, person which usually cooked for patient, source of drinking water used, age of caregiver, number of persons living in the same house as patient, monthly income per family, number of persons being supported from this income.

4. El Salvador caregivers who had ability to read obtained higher pre-test1 scores than caregivers unable to read. However, for caregivers in Guatemala, no significant relationship existed between the ability to read and the pre-test1 score.

5. There was no significant difference in score between post-test1 and post-test3 at 3 months or between post-test2 at 1 month and post-test3 at 3 months. (The majority of participants in the study did not take post-test3 at 3 months. Only eight caregivers in Guatemala did.)

6. There was no significant difference in pre-intervention knowledge between the two countries. Information acquisition of caregivers in El Salvador was significantly higher than that of caregivers in Guatemala.

7. There was no significant association between information acquisition and demographic variables in El Salvador and Guatemala.

8. There was no significant difference in socioeconomic status between El Salvador and Guatemala caregivers.

Chapter 5

DISCUSSION

Efficacy of the Educational Booklet

The main purpose of this study was to test the *Alimentación* booklet to determine if it was an efficient tool for education of low literacy caregivers of children with acute leukoblastic leukemia about food safety. Both knowledge acquisition and knowledge retention were tested. Knowledge acquisition was tested by comparison of pre-test1 and post-test1. Pre-test1 was designed to test caregiver's knowledge about food safety before education (pre-education knowledge). Post-test1 was administered immediately after education1. Pre- and post-test questions were identical. Significant differences were found between scores on pre-test1 and post-test1 in El Salvador ($p < 0.0001$) and in Guatemala ($p < 0.0001$). Therefore, it was concluded that the education with the *Alimentación* booklet was efficacious for teaching a low-literacy population about food safety.

Nevertheless it is unknown which part of the program contributed to the significant improvement of food safety knowledge. Several parts of the program could have impact on the information acquisition. For example, the educators' speech, which was memorized for consistency, could significantly improve the knowledge but not necessarily the *Alimentación* booklet. It is also possible that the speech had no impact. It is suggested that some aspects of the booklet may have an impact on learning. It could be the pictures, colors, or the size of the booklet. There are different styles of learning. Visual learners may like to learn by looking at the colors of the booklet and the simple pictures. Auditory learners may learn from listening to the nurse educators' speech.

Kinesthetic learners may benefit from the interactive questions or by actually preparing the meals for their child after the education intervention. Learning style of caregivers was not identified; therefore it is unknown which aspects of the *Alimentación* booklet contributed to the learning process and if there were differences in learning by caregivers' learning style. It is concluded that the whole program improved the caregiver's knowledge about food safety but it is unknown which part.

Pre-educational Knowledge

The study examined the relationship between pre-educational knowledge and demographic variables of the caregiver. Comparisons within and between countries were made. The following results apply to both El Salvador and Guatemala. No relationship was found between pre-education knowledge and gender of caregiver, the person who cooks for the patient, or having a stove, refrigerator, or microwave. No relationship was found in pre-educational knowledge and the relationship to the patient (mother, father or other) being the main cook in the family or water source family used. No relationship was found in pre-educational knowledge and the age of the caregiver, number of people living in the same household, family income, and how many people are supported from the income. The only significant relationship found was in pre-educational knowledge and self-reported ability to read in El Salvador. Caregivers who self reported ability to read obtained higher pretest scores than caregivers unable to read. However, for caregivers in Guatemala no significant relationship existed between pre-educational knowledge (pre-test) and the ability to read. Pre-education knowledge in El Salvador was compared with pre-education knowledge in Guatemala. No difference was found in pre-educational knowledge ($p = 0.1350$).

From the introduction section it is know that both countries differ by overall education level. The average people in Guatemala have 3.5 years of education and in El Salvador have 5.2 years of education (NationMaster, 2010). This concludes that on average caregivers from El Salvador are more educated than caregivers from Guatemala. It is not surprising to find that caregivers with the ability to read had higher pre-education knowledge than caregivers who were unable to read. Caregivers who can read have access to more education. What is surprising is that the same was not found in caregivers from Guatemala. It is possible that illiterate caregivers in El Salvador have been better identified than illiterate caregivers in Guatemala. In Guatemala non-significant differences in pre-educational knowledge in caregivers with self reported ability to read was found.

Association between information acquisition and demographic variables was tested by finding association between the difference of pre- and post- test in relationship to demographic variables. Data did not suggest the association of information acquisition with any variables: gender of caregiver, being the one who cooks for patient, having stove, refrigerator or microwave, self-reported ability to read, relationship to patients (mother, father, other), water source used, age of caregiver, number of people living in the same household, family income, how many people are supported from this income and socioeconomic status. Those findings support the prediction that there are no differences in caregivers in knowledge acquisition. For example, gender makes no difference in learning, which supports the already accepted fact in many countries that females and males have the same ability to learn. Unfortunately, as it is described in the literature review, in some countries there is still a trend to support boys in education but

not girls. Two-thirds of all illiterate people around the world are women (The Impact of Literacy, 2008). Additional evidence shows that no data are available on female illiteracy rate (NationMaster, 2010). Socioeconomic status also played no role in learning. It suggests that populations from a low income class have the same ability to learn as populations from a higher socioeconomic status. It also suggests as reviewed earlier in the literature review that illiteracy is due to lack of access to education and not due to inability to learn.

Acquisition of the Information

Comparison was made within and between countries. In El Salvador, the mean for correct answers from pre-test1 was 6.1 (*SD* ± 1.77) and the mean for correct answerers from post-test1 was 9.94 (*SD* ± 0.28). Maximum available points were 10. In Guatemala, the mean for correct answers from pre-test1 was 6.71 (*SD* ± 1.76) and the mean for correct answers for post-test1 was 8.47 (*SD* ± 1.52). Although pre-education scores do not differ significantly, there is a significant difference in post-test scores from El Salvador and from Guatemala, suggesting a possible difference in education. The nurse educators used the same memorized script, so the education was as similar as possible. However, some personality and even class characteristics could exist which may account for this difference. In El Salvador, all education was provided by the same female nurse educator. In Guatemala, some education was provided by a male nurse educator and some by a female dietitian.

Pre-educational scores were slightly higher in Guatemala than in El Salvador. On average, the education level of caregivers in Guatemala was lower than in El Salvador. First of all, in Guatemala, most children from high-income level families are treated in

private hospitals, in contrast to El Salvador where all children with leukemia are treated in the public hospital because private clinic for treatment of pediatric oncology patients does not exist. In general, El Salvador is a richer country than Guatemala. El Salvador's population has a higher educational level than Guatemala (NationMaster, 2010).

The education using the *Alimentación* tool was targeted to caregivers with low literacy levels. The previous nursing survey in each hospital reported that the majority of caregivers had low literacy levels and/or were unaccustomed to reading. As reported earlier, on average, people in Guatemala have 3.5 years of education and in El Salvador have 5.2 years of education (NationMaster, 2010). One of the questions asked "Can you read?" Therefore, it is a self-reported ability to read. Ninety percent of caregivers from El Salvador and 86% of caregivers from Guatemala reported that they could read. Therefore there is a discrepancy between literacy levels reported by caregivers and literacy levels reported by nursing staff. Nurse educators reported that ability to read can mean different things to different people. Some caregivers consider that they can read and write if they can sign their name, some caregivers may report ability to read if they can read numbers, others may report ability to read if they can read the alphabet. Therefore, because of the inadequate instrument design, an deficient response was obtained. Originally, in the survey, there was also a question about how many years of school education the caregiver had completed. This information was supposed to help distinguish between levels of education and the ability to read and write. This question, however, was taken out of the survey at the request of the Ethical Committee from the hospital. The committee thought that it could make caregivers feel inadequate if they completed just minimal years of school or did not go to school at all. In 2002, literature

revealed that in Guatemala 31% of the population was illiterate and 19% of the population in El Salvador was illiterate (NationMaster, 2010). Results from this study, regarding self-reported illiteracy were 10% of caregivers from El Salvador and 14% of caregivers from Guatemala reported inability to read. This discrepancy is because the ability to read is self reported and not further defined what research considered as ability to read.

Retention of the Acquired Information

Information retention was measured by administering the pre-test2 at one month after primary education. No significant differences were found between scores of post-test1 and pre-test2 in either country (Guatemala $p = 0.0781$, El Salvador $p = 0.0918$). In El Salvador, the mean for post-test1 and pre-test2 was 9.94 ($SD \pm 0.28$) and 9.88 ($SD \pm 0.37$), respectively. In Guatemala, the mean for post-test1 and pre-test2 was 8.47 ($SD \pm 1.52$) and 9.08 ($SD \pm 1.16$). A significant difference between pre-test1 and pre-test2 (El Salvador $p = 0.0001$, Guatemala $p = 0.0020$) was found, but not between post-test1 and pre-test2 (El Salvador $p = 0.0918$, Guatemala $p = 0.0781$).

Only in Guatemala, information retention was also measured by a post-test3 administered three months after primary education. No significant difference was found between the scores of pre-test2 (mean 9.08) and post-test3 (mean 9.38). Actually, the mean score of post-test3 was slightly higher than the mean score of pretest2. The slightly higher score can be explained by the fact that caregivers had time to practice the food safety diet daily by providing safe food for their children and, therefore, were reinforcing the learned information daily. Because no significant differences between pre-test2 and post-test3 after completion of the pilot study were found, the post-test3 was discontinued.

The researcher can also surmise, but not conclude, that retention of knowledge after education was provided is due to high motivation which is one of the characteristics of adult learners described by Knowles (1973). Caregivers of patients are motivated to learn about food safety so they can protect their child from getting food borne illnesses.

Influence of Demographic Variables on Information Acquisition and Retention

The second purpose of the study was to determine available food storage, cooking facilities, and forms of water supply in homes of the caregivers. The person who was interviewed (caregiver) was also the person who was usually cooking for the patient. In El Salvador, 78% of caregivers interviewed were also the main cook for the patient. In Guatemala, 69% of caregivers interviewed were also the main cook for the patient. This information is very important for targeting the education. This means that for 22% of patients in El Salvador and in 31% in Guatemala, the education about food safety was not provided to the person who actually prepares meals for patient. Therefore, the caregiver who brought the patient into the hospital would have to educate the main cook about food preparation and restrictions which are part of a neutropenic diet. This poses a risk that the education may not be provided well and that some information may be lost and, potentially, places the patient at risk for acquiring infection from the consumed diet.

Education should reach out to the main cook in the family which is not necessarily the person who brings the patient to the hospital. Compared to El Salvador, Guatemala had higher percentages of caregivers who are not the main cook for the patient bringing the patient to the hospital. This can be explained by the fact that Guatemala is a much larger country then El Salvador and many patients travel long distance to come to the hospital. It is likely, the mother, who in many cases is the main cook for the patient, has

to stay at home to take care of other siblings. Also, many times a child is sent to the hospital with a caregiver who is more literate. Bringing a child to the hospital requires skills which some rural caregivers may lack. For example, bringing a child to the hospital requires a long travel to the city, which may be intimidating. It also requires ability to read and sign documents, which can be challenging for a person with low literacy skills. Therefore, an older sister or aunt may be the one who brings the child to the hospital, rather than the person who is the main caregiver and cooks for the patient at home

The main cook in the family is usually the mother. The mother is the main cook in 79% of cases in El Salvador and in 86% of cases in Guatemala. The father is never the main cook in Guatemala (0%) and seldom in El Salvador (0.8%). The grandmother is the main cook in 6% of cases in El Salvador and in 11% of cases in Guatemala. "Other person" is the main cook in 13 % in El Salvador and 0% in Guatemala. The group "other" includes employee, aunt or sister. It is not uncommon that families living next to each other share a common place for cooking. One person is responsible for preparing meals for several related families. In higher socioeconomic levels, it is also common to have a paid person who prepares meals. The 13% of "others" in El Salvador who prepare meals for patients can be attributed to the fact that in El Salvador a mixture of high and low socioeconomic level families exists. Some higher socioeconomic level families may have an employee who is preparing food for the family and, therefore, also for the patient. The fact that mother is the most common person who brings the patient to the hospital and is most commonly the main cook reinforces the importance of the mother's literacy and education.

Cooking and storing facilities were evaluated by the availability of a stove, refrigerator and microwave. Methods of storing and cooking are very important to secure food safety. For example, if a family has no stove at home, meals are likely prepared in an outside oven. An oven located outside of the house can be a source of contamination by domestic animals and other pollutants. Seventeen percent of families in El Salvador and 39% of families in Guatemala have no gas or electric stove in the home. This is a clear indication of the difference in living standards in those two countries. This information is important for targeting proper education. For example, if almost 40% of the population in Guatemala has no stove, the recommendation to reheat food at a high temperature or to boil water for safety cannot be made because those recommendations could not be followed. Twenty-eight percent of families in El Salvador and 50% of families in Guatemala have no refrigerator. This information is also extremely important regarding food safety education. General food safety recommends keeping hot food hot and cold food cold to prevent bacterial multiplication. Hot food should be kept above 165°F and cold food should be kept below 40°F. Without owning a stove and refrigerator, those guidelines cannot be followed. Nevertheless, it is important especially in countries with a hot climate such as Guatemala and El Salvador. The average temperature in El Salvador is 73°F and in Guatemala is 68°F. If families have no refrigerator they should prepare all food fresh and preferably use only ingredients for cooking which do not require refrigeration such as rice, pasta or potatoes. Not having a microwave is also important. In El Salvador, 75% of caregivers do not have microwave and 69% in Guatemala. Having a microwave can help to reheat food to high enough temperature to kill possible bacteria.

By classifying these three variables (having stove, having refrigerator, and having microwave) in four groups, socioeconomic status of families could be estimated. If a family had a higher socioeconomic status, it is likely they would also own more appliances. It was expected that the lowest socioeconomic status families would have no stove, no refrigerator and no microwave and the highest socioeconomic status families would possess all three appliances. Fifteen percent of families in El Salvador and 39% of families in Guatemala were placed in the lowest socioeconomic status by not having any appliances. It can be hypothesized that those families probably have no electricity at home, since all appliances need electricity. Thirteen percent of families in El Salvador and 11% in Guatemala owned at least one appliance, 48% families in El Salvador and 19% families in Guatemala owned two appliances. Twentyone percent of families in El Salvador and 31% of families in Guatemala were placed in the highest socioeconomic group because they owned all three appliances. There was no significant difference found in socioeconomic status between those two countries.

Water supply families were using was also examined. Contaminated water is many times a source of infection. It is recommended that children who are neutropenic drink safe water. Safe water is considered the water treated by chlorine or bottled water. In many low income countries even public water can be a source of infection, especially in rural areas. Even for patients treated in the U.S.A., drinking water from the well is not recommended, as well as rain water and water from the river. The only safe source of water, recommended for patients living in El Salvador and Guatemala, is bottled water. Bottled water was used by 21 % of families in El Salvador and only by 8% of families in Guatemala. This can be explained by the cost of the bottled water which can be too

expensive for many families to buy. Six percent of families in El Salvador and 33% in Guatemala used municipal water. Municipal water is relatively safe, because it is brought to a location in large tanks and carried to local houses in containers. However, municipal water is not recommended for patients undergoing leukemia treatment due to possible contamination. Well water is used by 10% of families in El Salvador and 31% of families in Guatemala. Well water is not recommended, because of the possibility of contamination. Many wells are not checked for safety. Well water is probably the second most risky water for patients, preceded by drinking water from rivers and lakes. Tap water is used by 46% of families in El Salvador and no families in Guatemala. Tap water is usually available in the cities. In some cities, it is recommended that even tap water be boiled before using or that it is not used for cooking and drinking but only for washing. Other sources of water were used by 16% of families in El Salvador and 28% of families in Guatemala. The "other" group includes water purchased in large 10 gallon containers for home use. Water bought in large containers can be considered as safe as bottled water. Some people still use only rain or river water. Water from other sources, especially water from rivers or lakes, is high-risk water.

Significance

Several important findings were obtained by this study. The important feature of this study is that it is one of the first studies done to map low literacy caregivers and their knowledge acquisition in Guatemala and in El Salvador. Information collected during this study suggests the *Alimentación* booklet is an effective educational tool. Collected information includes data about cooking habits, food storage habits and food preparation habits in low-income families in Guatemala and El Salvador. It also includes information

about self reported ability to read and family size. The data provides insight on information acquisition and retention among different subgroups of low literacy caregivers. Findings between these two countries were compared. The study is unique in its scope because it tested the effectiveness of an educational intervention for low-literacy caregivers of pediatric oncology patients of low-income class in developing countries.

The *Alimentación* educational tool was found to be appropriate for teaching low literacy population about food safety. This booklet will be now distributed to all newly diagnosed patients with leukemia in both hospitals. Printing and distribution of the booklet is funded by American Lebanese Syrian Associated Charities (ALSAC).

Another significant finding of the study is the information about food storage and cooking facilities, which will help healthcare providers appropriately target patient education. For example, when half of the population does not have a refrigerator, caregivers should be instructed not to serve leftover food to patients. Because 40% of families do not have a stove at home and the majorities do not own a microwave, it should be recommended that patients consume only food which is low risk. For example, dry food is low risk, because bacteria need moisture to multiply. Eighty-two percent of the families do not drink safe water. Bottled water can be too expensive for families to purchase. Some programs recommend the use of chloride tablets for immunosupressed patients, other programs recommend exposing water to UV light (sun light) which may destroy bacteria. However, bottled water is the only safe water for patients but it is too expensive for caregivers to purchase. This issue remains an unsolved problem.

Another significant finding is that the learning capability of the caregiver does not depend on gender, age, relationship to patient, socioeconomic status or literacy level.

This finding is very important and supports the generally accepted idea that all people can learn if appropriate tools are used. Illiteracy was associated with lower pre-intervention knowledge in El Salvador only. This could possibly be explained by the illiterate population having less access to information developed for a low literacy population.

Limitations

This study has several limitations. The main limitation is that the literacy level of caregivers was not adequately tested due to self-reporting, and a variety of literacy levels. In the future, the literacy level should be assessed differently and in more detail. There were not two groups of caregivers, one which is literate and one which is illiterate. The group consists of a range of caregivers from high literacy to illiteracy. Literacy is self-reported, therefore, some caregivers may report that they are literate because they may be ashamed of their illiteracy. The question was formulated as "can you read?" This question may be interpreted differently by each caregiver. Many caregivers answered that they can read, but when asked an additional question they explained that they can read only their name. Some caregivers answered that they can read, but they meant that they can read only numbers. Another limitation is a small number of cases and a small number of completed questionnaires. In some cases, only the demographic questionnaire was available, in other cases only one pre-and post-test was available, because the caregiver could not be reached to provide the additional questionnaire one month later. Sometimes, the caregiver marked two answers instead of one and the questions had to be omitted from the evaluation. Lastly, the results cannot be generalized to the general population, but only to the group of caregivers of children with cancer who were treated in public hospitals in El Salvador and Guatemala. There also may be other factors that affect

learning, which were not studied. Some of the factors may be a severity of patient's disease, a stress level of caregiver, age of a patient, relationship with a medical staff, relationship with a nurse educator, and others.

Another limitation is a smaller group size of Guatemala caregivers compared to caregivers in El Salvador. Even though Guatemala is a larger country than El Salvador and has more patients diagnosed with leukemia the nurse educator and dietitian were unable to reach all caregivers. This is due to being busy with other clinical activities.

Implications for Future Research

Future research should be focused on how to adequately test literacy level. More research is also needed to find out how this educational intervention contributed to decrease of infection in pediatric oncology patients in Universidad Francisco Marroquin, Guatemala City, Guatemala, and Hospital Nacional de Niňos Benjamin Bloom in San Salvador, El Salvador. More data are also needed to find out if this educational intervention improved the survival rate of pediatric oncology patients in those two hospitals.

Future research should reach out to the main cook in the family which is not necessarily the person who brings the patient to the hospital. Compared to El Salvador, Guatemala had higher percentages of caregivers who are not the main cook for the patient bringing the patient to the hospital. This can be explained by the fact that Guatemala is a much larger country then El Salvador and many patients travel long distances to come to the hospital. It is likely, the mother, who in many cases is the main cook for the patient, has to stay at home to take care of other siblings. Also, many times a child is sent to the hospital with a caregiver who is more literate. Bringing a child to the hospital requires

skills which some rural caregivers may lack. For example, bringing a child to the hospital requires a long travel to the city, which may be intimidating. It also requires the ability to read and sign documents, which can be challenging for a person with low literacy skills. Therefore, an older sister or aunt may be the one who brings the child to the hospital, rather than the person who is the main caregiver and cook for patient at home.

There also may be other factors that affect learning, which were not studied. Some of the factors may be a severity of the patient's disease, a stress level of the caregiver, age of a patient, relationship with a medical staff, relationship with a nurse educator, and others.

It is not known why the *Alimentación* booklet worked, what elements or design of the booklet worked or what role the nurse educator played in making the booklet effective. More research is needed to investigate which parts of the educational program were the most effective to teach caregivers about food safety.

Since caregivers were not identified by their learning styles, it is unknown which aspects of the *Alimentación* booklet contributed to learning and if there were differences in learning by caregivers' learning style. It would be interesting to identify caregivers by learning style before education and to see if learning style affected the information acquisition using *Alimentación* booklet.

Lastly it is important to conduct more research in the area which is the main obstacle for caregivers; to follow the food safety diet guidelines at home and to prepare safe food for the patient. Those identified obstacles should be addressed to improve food safety compliance.

Recommendations Based on Findings

Based on this study, one on one education about food safety is recommended for caregivers because caregivers' knowledge about food safety before education was inadequate. It is also recommended that a standardized speech be used for consistency of education. The *Alimentación* booklet developed for low literacy caregivers to teach food safety is recommended for use in Guatemala and El Salvador. This booklet should be given to caregivers after education. It is recommend reviewing food safety with caregivers monthly and answering potential questions.

This booklet shouldn't be used in other countries. A modification of this booklet should be developed if it is going to be used in countries other than in Guatemala and El Salvador. When adapting the *Alimentación* booklet for use in other countries, cultural food and cooking habits should be considered.

It is also recommended that information about cooking and storing food be individualized based on available cooking and storing facilities each caregiver or family has.

It is also recommended families receive assistance in securing a safe water supply for patients. If bottled water cannot be provided for the patient, caregivers should be educated to boil water for 5 minutes to destroy bacteria.

It is strongly recommended the mother be educated as the primary caregiver and cook for the patient.

Conclusion

This study had three purposes:

1) to test efficacy of the Alimentación booklet, as an educational intervention for low- literacy population. Pre-and post-test was used to determine information acquisition and information retention. The study found the *Alimentación* booklet is an efficient tool for teaching low literacy caregivers about food safety. Information retention remained high one and three months after education;

2) to determine available food storage, cooking facilities and water supply available to the studied population. The study found that caregivers have inadequate cooking and storing facilities. Half of caregivers do not have a refrigerator to store food, forty percent of caregivers do not have a stove and 75% have no microwave. The majority of families do not have access to water which is safe for the patient;

3) to identify which variables affect information acquisition and information retention in the study population. None of the variables tested affected information acquisition (learning) or information retention which remained high one and three months after education

This project is an excellent example of international collaboration between three countries U.S.A, Guatemala, and El Salvador. It is also an example of collaboration between low income countries and high income countries. Many disciplines participated on this project including medical doctors, nurses, dietitians, designers and educators. This project shows that international collaboration and multidisciplinary collaboration is possible and can significantly improve management of pediatric oncology patients from low income countries.

REFERENCES

Angele, M., Loehe, F., & Faist, E. (2005). Immunomodulation during sepsis in organ transplanted children. *Minerva Pediatr, 57,* 259-68.

Chen, Y., & Li, H. (2009). Mother's education and child health: Is there a nurturing effect? *Journal of Health Economic, 28*(2), 413-26.

Davis, L. (1992). Instrument review: getting the most from your panel of experts. *Applied Nursing Research, 5,* 104-107.

De Rivera, I., Amador , L., Mourra, S., Li, Z., & Rasheed, S. (1995). Geographical clustering of human T-cell lymphotropic virus type 1 infection in Honduras. *Journal of Clinical Microbiology, 33,* 2999-3003.

Fischer, S. (2003). *History of Writing*. London: Reaktion Books.

French, K., & Larrabee, J. (1999). Relationships among educational material readability, client literacy, perceived beneficence, and perceived quality. *Journal of Nursing Care Quality, 13*(6), 68-82.

Frenkel, J., Hassanein, K., Hassanein, R., Brown, E., Thulliez, P., & Quintero-Nunez, R. (1995). Transmission of toxoplasma gondii in Panama City, Panama: A five-year prospective cohort study of children, cats, rodents, birds, and soil. *American Journal of Tropical Medicine and Hygiene, 53,* 458-68.

Freire, P. (1921). *Pedagogy of the Oppressed* (20th ed.). New York: Continuum.

Freire, P. (1976). *Education, the Practice of Freedom*. London: Writers and Readers Publishing Cooperative.

Fries, E., Edinboro, P., McClish, D., Manion, L., Bowen, D., & Beresford, S. (2005). Randomized trial of a low-intensity dietary intervention in rural residents: The rural physician cancer prevention project. *American Journal of Preventive Medicine, 28*(2), 162-8.

Forest , G. (2004). Gastrointestinal infections in immunocompromised hosts. *Gastroenterology, 20,* 16-21.

Garcia, M., Chismark, E., Mosby, T., & Day, S. (2010). Development and Validation of a Nutritional Educational Pamphlet for Low-literacy Pediatric oncology Caregivers in Central America. *Journal of Cancer Education, 25(4):512-7.*

Grant, J., Kinney, M., & Guzzetta, C. (1990). A methodology for validating nursing diagnoses. *Advances in Nursing Science, 12*(3), 65-74.

Grant, J., & Davis, L. (1997). Selection and use of content experts for instrument development. *Research in Nursing & Health, 20,* 269-274.

Health Literacy. (2010). Retrieved March 18, 2010, from Wikipedia Web Site: http://en.vikipedia.org/viki/Health_literacy

Hesling, P. (2010). Personal Interview. Ghana, 2010.

Houts, P., Bachrach, R., Witmer, J., Tringali, C., Bucher, J., & Localio, R. (1998). Using pictographs to enhance recall of spoken medical instructions. *Patient Education and Counseling, 35*(2), 83-88.

Houts, P., Doak, C., Doak, L., & Loscalzo, M. (2006). The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling, 61*(2), 173-190.

Hubley, J. (2006). Patient education in the developing world: A discipline comes of age. *Patient Education and Counseling, 61*(1), 161-164.

Howard, S. C., Metzger, M. L., Wilimas, J. A., Quintana, J., Ching-Hon, P., Robison, L., et al. (2007). Childhood cancer epidemiology in low-income countries. *Cancer, 112*(3), 461-472.

Knowles, M. (1973). *The Adult Learner. A neglected species* (4th ed.). Huston: Gulf Publishing.

Lindeman, E. (1961). *The Meaning of Adult Education*. Canada: Harvest House Ltd.

Lownd, P. (n.d). *A Brief Bibliography of Paulo Freire's life and work by Peter Lownd*. Retrieved March 18, 2010, from Freire's Life and Work Web Site: http://dmnerweber.iweb.bsu.edu/teachingguide/freire%20bio.html

Lynn, M. (1986). Determination and quantification of content validity. *Nursing Research, 35*(6), 382-385.

Macario, E., Emmons, K., Sorensen , G., Hunt, M., & Rudd, R. (1998). Factors influencing nutrition education for patients with low-literacy skills. *Journal of the American Dietetic Association, 98,* 559-564.

Mc Kinney, J.& Kurtz-Rossi, S. (2000). Culture, Health and Literacy. World Education 2000. http://healthliteracy.worlded.org/docs/culture/index.html. Retrieved 11/30/2010

Moody, K., Finlay, J., Mancuso, C., & Charlson, M. (2006). Feasibility and safety of a pilot randomized trial of infection rate: Neutropenic diet versus standard food safety guidelines. *Journal of Pediatric Hematology and Oncology, 28,* 126-33.

Mosby, T., Day, S., Challinor, J., Hernandez, A., Garcia, J., & Valasquez, S. (2008). Nutritional issues in pediatric oncology: An international collaboration between the central American nurses cooperative group and U.S. - based dietary and nursing experts. *Pediatric Blood & Cancer, 50,* 1298-1300.

Mosby, T., Mullins Nelson, B., Garcia, M., Hernández, A., García, J., Day, S., & Caniza, M. (2009). Evaluating the efficacy of a nutritional education pamphlet for pediatric oncology caregivers in Central America, SIOP 2009, Sao Paulo, Brazil, October 5-12.

National Assessment of Adult Literacy. (2003). Retrieved March 17, 2010, from National Center for Education Statistics Web Site: http://nces.ed.gov/naal/

NationMaster.com. (2010). Retrieved March 31, from Education Statistics, Literacy, Adults at low-literacy level by country. http://www.nationmaster.com/graph/edu_lit_adu_at_low_lit_lev-education-literacy-adults-low-level

Ngoh, L., & Shepherd, M. (1997). Design, development, and evaluation of visual aids for communicating prescription drug instructions to nonliterate patients in rural Cameroon. *Patient Education and Counseling, 31*(3), 245-261.

Ravilious, K. (2010). The Writing on the Cave Wall. *NewScientist, 2748,* 30-34.

Reardon-Anderson, J., Capps, R., & Fix M. (2002). The health and well-being of children in immigrant families. *New Federalism National Survey of America's Families*. The Urban Institute, Series B., No. B-52, November 2002.

Sala, A., Pencharz, P., & Barr, R. (2004). Children, cancer, and nutrition: A dynamic triangle in review. *Cancer, 100*(4), 677-687.

Sobel, R., Paasche-Orlow, M., Waite, K., Rittner, S., Wilson, E., & Wolf, M. (2009). Asthma 1-2-3: A low-literacy multimedia tool to educate African American adults about asthma. *Journal of Community Health, 34,* 321-327.

Standards for educational and psychological testing. (1985). Washington, DC: American Educational Research Association, American Psychological Association, National Council on Measurement in Education.

The impact of literacy. (2010). Retrieved March 18, 2010, from ProLiteracy Web Site: http://www.proliteracy.org/NetCommunity/page.aspx?pid=345&srcid=269

Todd, J., Schmidt, M., Christain, J., & Williams, R. (1999). The low-bacteria diet for immunocompromised patients: Reasonable prudence or clinical superstition? *Cancer Practice, 7*(4), 205-207.

UNESCO (2004). UNESCO Education Sector, The Plurality of Literacy and its implications for Policies and Programs: Position Paper. Paris: United National Educational, Scientific and Cultural Organization, 2004, p. 13, citing an international expert meeting in June 2003 at UNESCO.

United Nations.(2006). International Migration 2006, United Nations, Department of Economic and Social Affairs, Population Division. United Nations Publication, No. E.06.XIII.6, March 2006.

United Nations. (1948). *The Universal Declaration of Human Rights*. Retrieved February 15, 2011, from United Nation Web Site: http://www.un.org/en/documents/udhr/index.shtml

US Department of State. (2009). Retrieved March 31, 2010 from U.S. Department of State Web Site http://www.state.gov/r/pa/prs/ps/2009/nov/131995.htm

Wang, T. S., & Deng, J. C. (2007). Molecular and cellular aspects of sepsis-induced immunosuppression. *Journal of Molecular Medicine, 2007*.

Zimmerman, M., Newton, N., Frumin, L., & Wittet, S. (1989). Developing health and family planning print materials for low-literate audiences: A guide. Washington, DC.: Program for Appropriate Technology in Health,1989.

APPENDICES

Appendix A: Booklet *Alimentación*


¿Qué puedo hacer para evitar la
dar a mi hijo (a)?
Evite comprar comida en la calle.
COMIDA
Solo coma en restaurantes recomendados por su equipo médico.
Mantenga separada la carne de las frutas y los vegetales.
Siempre lávese las manos con agua y jabón antes y después de preparar la comida.
Té
Nueces sin cocción
Pasas u otras frutas secas
Carnes crudas o no bien cocidas
Huevos que no estén bien cocidos

¿Qué le puedo dar a mi hijo (a)?

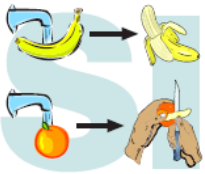
Agua y otros refrescos en botellas, latas u otros envases comerciales

Café caliente

Leche, queso, crema, yogurt y otros productos lácteos pasteurizados

Alimentos enlatados o sellados en una caja, bolsa u otro envase (empacados)

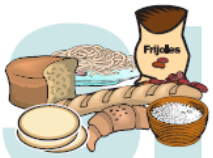
Frutas lavadas y peladas.



Vegetales lavados y cocidos.

★Si es posible, pele los vegetales.

Tortillas, frijoles, arroz, panes y pastas.



Todas las carnes y huevos bien cocidos.

¿Qué NO le debo contaminación de la comida?

Agua de la llave sin hervir

Hielo hecho solo si usó agua segura

Frutas que no se puedan pelar como las fresas, las uvas y los nances

Ensaladas y vegetales crudos

Sazone o condimente la comida durante cocción.

Coma la comida recién hecha.

No recaliente la comida. Nunca le dé sobras a su niño (a).

Mantenga limpias las superficies donde corta, prepara y come la comida.

Lave los utensilios, platos, vasos, ollas y otros envases con agua y jabón.

Appendix B: Nurse Educator's Talk

(Nurse educator memorized the following script (in italics) and used it along with the booklet)

1. Welcome participants and thank them for making time for participating in this study
2. Introduce your self: *"My name is _____ and I am a Nurse Educator for this hospital".*
3. Explain the objectives of the study
    a. *"The reason for this study is to find out the efficacy of an educational tool to teach caregivers about food safety. Your participation is voluntary. First we will ask you ten multiple choice questions about food safety. You will choose one answer. Then we will provide education using an educational tool "Alimentación del niño con cáncer". After providing this education we will ask you the same questions again and you will choose one answer. After that we will ask you to fill out a Demographic Questionnaire. The whole session will take about 30 minutes. You can keep the booklet. Would you like to participate?"*
    b. If the participant agrees to participate, go to step # 4. If not, thank them for their time.

4. Read and explain the Consent Form to the participant. Ask if they have any questions. Answer their questions. If they agree to participate, ask them to sign both

copies of the Consent Form. Give one copy of Consent Form to the participant and place the other one in the folder.

5. Put patient's number in the upper right corner of the Consent Form, the Pre and Post-tests, and of the Demographic Questionnaire

6. Administer the Pre-test Questionnaire. If the participants are literate they can fill out the Pre-test Questionnaire by themselves. If they are illiterate, you will read each question and each answer to the participants and mark the answer they choose. Place Pre-test Questionnaire in the folder.

7. Provide education using educational tool "ALIMENTACIÓN DEL NIÑO CON CÁNCER".

a. *"Children with cancer of the blood have poor immunity due to the disease and the anticancer treatment. This means that they cannot fight infections as you and I can. Therefore they have to follow special food safety guidelines to protect them from getting sick from food. If they get sick from food their treatment may get complicated or they may die.*
b. *We will review basic food safety guidelines which are pictured in this booklet. Please ask questions anytime during this education.*
c. *Children undergoing anticancer treatment should not have food bought on the street or in the restaurant because we don't know how old the food is, if it is contaminated or if the food was handled by a sick person.*

d. *Always use a different cutting board or cutting area for meats and for vegetables.*

e. *When you are preparing food for your child, wash your hands with soap and clean water before and after cooking.*

f. *When you season meals for your child use seasoning and dry herbs before cooking and NOT after cooking. Some spices may contain spores of bacteria and by using those after cooking you may contaminate the whole meal.*

g. *Your child should always have freshly made food. Avoid giving your child leftovers. In leftovers, bacteria will continue to multiply and food may become unsafe for patient.*

h. *Always keep all cooking surfaces clean and wash all dishes and utensils with clean water and soap.*

i. *Your child can have any bottled drinks (bottled water, juice box, coke,..)*

j. *Your child can have freshly made coffee or chocolate. Use only boiled or bottled water for preparation.*

k. *Your child can have any pasteurized milk products. Avoid un-pasteurized milk or cheese.*

l. *Your child can have any freshly open can food or food commercially prepackaged. For example cereals, crackers, candy, …*

m. *Your child can have any fruit that was washed and peeled, canned or cooked.*

n. *Your child can have all vegetables which were washed and peeled, canned or cooked.*

o. *Your child can have freshly prepared breads, rolls, beans, rice and tortillas.*

p. *Your child can have all fresh and well cooked meats and eggs.*

q. *There are a few things which your child should not have because it can contain bacteria, which can make your child very sick*

r. *Your child should NOT have tap water or water from the well.*

s. *Your child also should NOT have any ice made from tap water or water from the well.*

t. *Your child should NOT have fruit which can't be peeled. For example strawberries, grapes and nances.*

u. *Your child should NOT have uncooked or unpeeled vegetables – for example lettuce.*

v. *Your child should NOT drink tea made from tea leaves or tea bags because it can be contaminated with bacteria.*

w. *Your child should NOT have dry uncooked fruit and nuts. For example raisins. Your child can have raisins in the pastry because those raisins are cooked.*

x. *Your child should NOT have uncooked meat or smoked meat. Because the smoking temperature is not high enough to kill all the bacteria.*

y. *Your child should NOT have sunny side up eggs (only well cooked eggs) and should NOT have any products where raw eggs are used.*

z. *This diet which is low in bacteria can prevent your child from getting an infection from food.*

aa. *Remember bacteria do not have any color, smell, or taste that is why it is difficult to recognize contaminated food*

bb. *For children with cancer, it is very important to follow a diet low in bacteria during their treatment.*

cc. *Do you have any questions?"*

8. Answer all caregivers' questions and ask them to review the booklet one more time. Give them as much time as they need to look over the booklet. After they have reviewed the booklet and asked questions, collect the booklet and go to step 5.

9. Administer Post-test Questionnaire the same way you administered the pre-test. Check if the patient's number is in the upper right corner.

10. Administer Demographic Questionnaire. Check if the patient number is in the upper right corner.

11. Thank the participants for their time and give them the booklet to keep.

Apéndice B: Discurso del enfermero educador

1. Dar la bienvenida al participante y las gracias por su tiempo.

2. Introducción: *"Mi nombre es _____ y soy el(la) enfermero(a) educador(a) de este hospital."*

3. Explicar los objetivos de la investigación

   a. *"La razón por lo cual esta investigación se lleva acabo es para averiguar la eficacia de un instrumento educativo para enseñarle a los padres o guardianes sobre la seguridad alimenticia. Su participación es voluntaria. Primero le solicitaremos que complete una prueba de diez preguntas de selección múltiple sobre la seguridad alimenticia. Solo podrás escoger una respuesta por cada pregunta. Después de la prueba, le presentaremos una sesión educativa usando el folleto bajo investigación titulado "Alimentación del niño con cáncer". Después de esta sesión educativa, completaras la misma prueba administrada antes de la sesión educativa. Le solicitaremos que llenes una encuesta demográfica. La investigación solo durará aproximadamente 30 minutos en total. Se podrá quedar con el folleto. ¿Le gustaría participar?*

   b. Si el padre o guardian accede participar, siga al paso #4. Si no le interesa participar déle las gracias por su tiempo.

4. Lea el formulario de consentimiento al participante. Pregunte si tiene algunas preguntas. Conteste sus preguntas. Solicite su firma en las dos copias del formulario de consentimiento. Dele un formulario al participante y coloque el otro en la carpeta.

5. Escriba el número del paciente en el formulario de consentimiento y las calificaciones de las pruebas administradas antes y después de la sesión educativa en la esquina superior derecha de la encuesta demográfica.
6. Administre la prueba preliminar. Si el participante puede leer, puede completar la prueba sin ayuda. Si el participante no puede leer, léale cada pregunta con las opciones de respuestas y marque la respuesta que el o ella escoja. Cuando se halla completado la prueba colóquela en la carpeta.
7. Provee educación utilizando el instrumento educativo titulado "Alimentación del niño con cáncer".
    a. *"Niños con cáncer de la sangre tienen baja inmunidad causada por la enfermedad y su tratamiento. Esto significa que no pueden luchar contra las infecciones como usted y yo. Por eso tienen que seguir pautas especiales sobre la seguridad alimenticia para protegerlos contra las enfermedades transmitidas por alimentos. Si se llegan a enfermar a causa de los alimentos, su tratamiento se puede complicar o se pueden hasta morir.*
    b. *Vamos a repasar las pautas básicas de la seguridad alimenticia que se encuentran en este folleto. Por favor no dudes en hacerme cualquier pregunta durante esta sesión.*
    c. *Niños recibiendo tratamiento contra el cáncer no deben comer los alimentos comprados en la calle o en un restaurante porque no se sabe si la comida esta fresca o pasada, o si está contaminada o ha sido manipulada por alguien que esté enfermo.*

d. *Siempre use tablas de cortar o áreas de cortar separadas para la carne y los vegetales y frutas*.

e. *Cuando estés preparando comida para su hijo(a), lávese las manos con jabón y agua limpia antes y después de cocinar*.

f. *Cuando condimentes los alimentos para su hijo(a) use sazones y hierbas secas <u>antes</u> de la cocción y evite su uso después de la cocción. Algunos condimentos contienen esporas de bacteria y si los usas después de la cocción puedes contaminar la comida entera.*

g. *Su hijo(a) debe comer solamente alimentos recién hechos. Evite darle sobras a su hijo(a). Las sobras de comida contienen bacteria que se siguen multiplicando y la comida puede llegar a ser peligrosa para el paciente.*

h. *Siempre mantenga las superficies donde cocina limpias y lave todos los trastes y utensilios con jabón y agua limpia.*

i. *Su hijo(a) puede beber cualquier bebida embotellada (agua embotellada, jugos en caja, refrescos,..)*

j. *Su hijo(a) puede beber café o chocolate recién hecho. Use solamente agua hervida o agua embotellada en su preparación.*

k. *Su hijo(a) puede comer o beber cualquier producto lácteo si esta pasteurizado. Evite la leche y el queso que no esté pasteurizado.*

l. *Su hijo(a) puede comer cualquier alimento enlatado recién abierto o alimentos empacados comercialmente. Unos ejemplos son los cereales, galletas, dulces, ...*

m. *Su hijo(a) puede comer cualquier fruta que sea lavada y pelada, enlatada o cocida.*

n. *Su hijo(a) puede comer cualquier vegetal que sea lavado y pelado, enlatado o cocido.*

o. *Su hijo(a) puede comer panes, panecillos, frijoles, arroz y tortillas recién hechos.*

p. *Su hijo(a) puede comer carnes y huevos frescos que estén bien cocidos.*

q. *Hay algunos alimentos que su hijo(a) no debe comer o beber porque pueden contener bacteria, lo que puede producir enfermedades graves.*

r. *Su hijo(a) <u>no debe</u> beber agua de la canilla o del pozo.*

s. *Su hijo(a) <u>no debe</u> ingerir hielo hecho con agua de la canilla o del pozo.*

t. *Su hijo(a) <u>no debe</u> comer frutas que no se puedan pelar. Por ejemplo las fresas, uvas y nancees.*

u. *Su hijo(a) <u>no debe</u> comer vegetales crudos o sin pelar. Por ejemplo la lechuga*

v. *Su hijo(a) <u>no debe</u> beber té hecho con hojas de té o bolsitas de té porque pueden estar contaminadas con bacteria.*

w. *Su hijo(a) <u>no debe</u> comer frutas o nueces secas y sin cocción. Por ejemplo las pasas. Su hijo(a) puede comer pasteles con pasas porque esas pasas son cocidas.*

x. *Su hijo(a) <u>no debe</u> comer carnes crudas o ahumadas. La temperatura para ahumar las carnes no es suficientemente alta para destruir toda la bacteria.*

y. *Su hijo(a) <u>no debe</u> comer huevo frito. Solamente puede comer huevos que estén bien cocidos. Adicionalmente, su hijo(a) <u>no debe</u> comer o beber productos que contienen huevos crudos.*

z. *Esta dieta baja en bacteria puede prevenir las infecciones causadas por la presencia de bacteria en los alimentos.*

aa. *Recuerda que la bacteria no tiene olor, sabor o color y por esta razón es difícil saber cuales comidas contienen bacteria.*

bb. *Para la protección de las personas con cáncer es importante que sigan una dieta baja en bacteria durante su tratamiento.*

cc. *¿Tiene algunas preguntas?*

8. Conteste todas las preguntas y solicite que los participantes repasen el folleto nuevamente. Proporcione todo el tiempo que necesitan mientras repasan la información en el folleto. Después que hallan repasado el folleto y hecho preguntas, recoja el folleto y siga al paso #8.
9. Administre la prueba del mismo modo que administró la prueba preliminar. Asegure que el numero del paciente este escrito en la esquina superior derecha de la prueba.

10. Administre la encuesta demográfica. Asegure que el numero del paciente este escrito en la esquina superior derecha de la encuesta.
11. Déle gracias al participante por su tiempo y entréguele el folleto de nuevo.

Appendix C: Pre and Post-test Questionnaire:

(Correct answers are in bold for convenience of reader only)

Patient number _____

Please, choose one answer which you think is correct and circle corresponding letter

1. Children with cancer

    a. Have the same immunity as children without cancer

    b. Have to follow a special diet because they can't fight infection properly

    c. Can eat what ever they ask for

    d. Can't eat any food prepared at home

2. My child can have food

    a. Bought in front of the hospital from a food vendor

    b. Foods I cooked last night, covered it and left it on the counter.

    c. Freshly prepared food

    d. Food from the local restaurant

3. When I am preparing food for my child

    a. I use the same cutting board for meat and for vegetables

    b. I wash my hands with clean water and soap before and after cooking

    c. I wash the plates just with water and never use soap

    d. I need to wash my hands only after cooking

4. When I am cooking

    a. I will use spices (for example pepper) after the meal is cooked

    b. I will reheat leftover food from last night

    c. I will serve only freshly made food to my child

5. I will let my child drink

    a. Tea

    b. Tap water with lemon and sugar

    c. Bottled water which I just opened the seal

    d. Milk from the neighbor's cow

6. A fruit that my child can have is

    a. pealed banana

    b. strawberry

    c. grapes

    d. my child can't have any fruit

7. Vegetables that my child can have are

    a. Recently cooked vegetables

    b. Lettuce

    c. Cooked vegetables from yesterday

    d. My child can't have any vegetables at all

8. Food that my child CANNOT have are

   a. Refried beans

   b. Bread with butter

   c. Tortilla with cheese

   d. Rice from yesterday

9. Protein-rich food that my child CANNOT have are

   a. Boiled eggs

   b. Well-done steak

   c. Sunnyside up eggs

   d. Well-done fish

10. Food that my child can have are

   a. Raisins

   b. Ice made from tap water

   c. Raisin bread

   d. Home made mayonnaise prepared from raw eggs

Appendix C: Spanish Version

Numero del paciente _____

Por favor escoja la respuesta que crea que es correcta. Solo hay una respuesta.

1) Niños con cáncer
   a) Tienen la misma inmunidad (defensa) que los niños sin cáncer
   b) Tienen que seguir una dieta especial porque no pueden combatir infecciones apropiadamente
   c) Pueden comer cualquier cosa que piden
   d) No pueden comer comida preparada en casa

2) Mi hijo(a) puede ingerir alimentos
   a) Comprados de vendedores ambulantes al frente del hospital
   b) Que cociné ayer y dejé cubiertos fuera de la nevera anoche
   c) Recién hechos
   d) De un restaurante que no es recomendado por el doctor

3) Cuando estoy preparando comida para mi hijo(a)
   a) Puedo cortar la carne y los vegetales usando la misma tabla de cortar
   b) Tengo que lavarme las manos con agua limpia y jabón antes y después de cocinar
   c) Esta bien si lavo los platos con agua solamente y nunca uso jabón
   d) Necesito lavarme las manos solamente después de cocinar

4) Cuando estoy cocinando
    a) Puedo usar condimentos (el pimentón, por ejemplo) después que la comida esté cocida
    b) Puedo recalentar las sobras de anoche
    c) Debo servirle solamente comida recién hecha a mi hijo(a)
    d) Puedo recalentar el arroz de ayer

5) Yo dejaría que mi hijo(a) beba
    a) Té
    b) Agua de la canilla con limón y azúcar
    c) Agua embotellada recién abierta
    d) Leche de la vaca de mi vecino

6) Una fruta que puede comer mi hijo(a) es
    a) Un banano recién pelado
    b) Fresas después de enjuagar
    c) Uvas después de enjugar
    d) Mi hijo(a) no puede comer frutas

7) Vegetales que mi hijo(a) puede comer son
    a) Vegetales recién cocidos
    b) Lechuga

c) Vegetales recalentados de ayer

d) Mi hijo(a) no puede comer vegetales

8) Un alimento que mi hijo(a) no puede comer es

a) Frijoles refritos

b) Pan con mantequilla

c) Tortilla con queso

d) Arroz cocido ayer

9) Un alimento rico en proteína que mi hijo(a) no puede comer es

a) Huevo duro

b) Carne bien cocida

c) Huevo frito

d) Pescado bien cocido

10) Un alimento que mi hija(o) puede comer es

a) Uvas pasas

b) Hielo hecho con agua de la canilla

c) Pastel hecho con uvas pasas

d) Mayonesa preparada en casa con huevos crudos

Appendix D: Demographic Questionnaire

Patient number _____

Demographic Questionnaire

Your name: _____

In relation to patient you are his/her? _____

Patient name: _____

Gender: female male

Age: _____

How many people living in the house:

1 2 3 4 5 6 7 8 9 10 10+

Are you the one that usually prepare meals for patient?

Yes No

Who is the main cook in your household (in relation to patient)?

Mother Father Grandmother Grandfather Other

Do you have electric or gas stove? Yes No

Do you have refrigerator? Yes No

Do you have microwave? Yes No

Your water source is?

Municipal tap water well bottled water other (please specify)

Can you read: yes no

Appendix D: Demographic Questionnaire, Spanish Version

Numero del paciente _____

Encuesta demográfica

Su nombre: _____

Relación con el paciente: _____

Nombre del paciente: _____

Sexo: masculino femenino

Edad: _____

¿Cuantas personas viven en su hogar? 1 2 3 4 5 6 7 8 9 10 10+

¿Eres la persona que usualmente prepara la comida para el paciente?
Sí No

¿Quien es el cocinero principal en su hogar? (relación con el paciente)

Mamá Papá Abuela Abuelo Otro

¿Tiene estufa eléctrica o de gas? Sí No

¿Tiene un refrigerador? Sí No

¿Tiene una microonda? Sí No

¿De donde proviene el agua?

Agua de la canilla (municipal) Agua del pozo Agua embotellada Otro

¿Puede leer? Sí No

Appendix E: Content Validity Testing

Content Validity Testing

I am inviting you to serve as a Content Expert on a project about a food safety educational tool as an important infection control strategy.

Would you please review the 10-item questions on the attached sheet?

After you have read each item, would you please decide if the item fits in one of the three categories below? Place a check mark (√) in the column of the category that you believe the item best fits

DOMAIN:

Category One: General Conception (identifying the appropriate diet for a child with cancer)

Category Two: Food Preparation (defined as: the proper way to handle food items for patients with cancer is to prevent foodborne illness infection).

Category Three: Allowance/ Restrictions of food items (defined as: identifying foods that are at higher risk for bacterial growth which would increase the risk of infection secondary to foodborne illness).

If an item does not fit one of the domains of food safety, leave that row blank (no check marks)

CLARITY:

Next, please indicate if the questions are clear and accurate by ranking them from 1-4.

The ranking is defined as the following:

1. Question does not represent the category at all.*
2. Question needs major revisions. *

3. Question needs minor revision. *

4. Question needs no revisions. *

*Please describe further in detail at the last page of this attachment.

ACCURACY:

Then, please indicate in the final column labeled accuracy if the correct answer to the item is part of the options or if a better response option needs to be added.

Finally, let us know if we left anything out that might be important related to food safety guidelines.

Thank you,

Terezie Tolar Mosby MS, RD, CSP, IBCLC

Appendix F: IRB SJCRH

INSTITUTIONAL REVIEW BOARD #29
FWA00004775

June 22, 2009

Terezie Mosby, MS, RD, LDN, IDCCC
CLINICAL NUTRITION

Dear Ms. Mosby:

RE: **XPD08-054** - Evaluation of Efficacy of Food Safety Educational Program Using an Educational Tool for a Low-Literacy Population

This is to certify, that, on **June 19, 2009**, the **continuing review application received from Dr. Mosby**, submitted to the Institutional Review Board for consideration was reviewed by an IRB member, using expedited procedures with respect to the adequacy of protecting the rights and welfare of participants, the use of appropriate methods of securing informed consent, the measures to be taken to minimize risk and the degree of risk relative to the potential benefits of the proposed research.

IRB Review Status: **Approved under 45CFR46.110(b)(1) and 21CFR56.110(b)(1), category # 7 for the period of one year beginning 6/25/2009 through 6/24/2010.** For assistance, please contact the Office of Human Subjects' Protection at 901-595-4357 or email hsp-1@stjude.org.

Teresa Carr, RN, BS, CCRC, CIM, OHSP Interim Director

2009 Review for (CR00000785)

Reminder of Principal Investigator Responsibilities:

As previously signed and certified, approval of this research involving human subjects is contingent upon your agreement:
1. To report to the Institutional Review Board for Human Research (IRB) any adverse effect or research related injuries which might occur in relation to the human experimentation. To read and comply with IRB reporting
2. To submit in writing for prior IRB approval any alterations to the plan of human research.
3. To submit timely continuing review reports of this research as requested by the IRB.
4. To maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.
5. To notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this institution and the project.

CC: Terezie Mosby

Institutional Review Board #29
FWA00004775

June 4, 2010

Terezie Mosby, MS, RD, LDN, IDCCC

CLINICAL NUTRITION

RE: **XPD08-054** - Evaluation of Efficacy of Food Safety Educational Program Using an Educational Tool for a Low-Literacy Population

Dear Ms. Mosby,

This is to certify that, on **June 3, 2010**, the

2010 Continuing Review Report and Closure to Accrual Notification received 6/1/2010
submitted to the Institutional Review Board for consideration was reviewed by an IRB member using expedited procedures with respect to the adequacy of protecting the rights and welfare of participants, the use of appropriate methods of securing informed consent, the measures to be taken to minimize risk and the degree of risk relative to the potential benefits of the proposed research.

IRB Review Status:

The continuing review report is approved as submitted under 45CFR46.110(b)(1), research category #7, and the minimal risk research is re-approved for a period of one year under children's research category 45CFR46.404.

IRB Approval Date: 6/3/2010

IRB Expiration Date: 6/25/2011

For further assistance, please contact the Office of Human Subjects' Protection at 901-595-4357 or email hsp-1@stjude.org.

Kathleen Price, RN, MBA, OHSP Director

(Submission Link: CR00001473)

Reminder of Principal Investigator's Responsibilities:

As previously signed and certified, approval of this research involving human subjects is contingent upon your agreement:

1. To report to the Institutional Review Board for Human Research (IRB) any adverse effect or research related injuries which might occur in relation to the human experimentation. To read and comply with IRB reporting guidelines.

2. To submit in writing for prior IRB approval any alterations to the plan of human research.

3. To submit timely continuing review reports of this research as requested by the IRB.

4. To maintain copies of all pertinent information related to the research activities in this project, including copies of informed consent agreements obtained from all participants.

5. To notify the IRB immediately upon the termination of this project, and/or the departure of the principal investigator from this institution and the project.

St Jude Children's Research Hospital

Memphis, Tenn.

Appendix G: IRB The University of Memphis

THE UNIVERSITY OF MEMPHIS

Institutional Review Board

To:	Terezie Tolar Mosby Adult and Higher Education
From:	Chair, Institutional Review Board For the Protection of Human Subjects irb@memphis.edu
Subject:	EVALUATION OF INFORMATION ACQUISITION AND INFORMATION RETENTION USING A LOW-LITERACY BOOKLET FOR ILLITERATE CAREGIVERS OF CHILDREN WITH LEUKEMIA (012611-401)
Approval Date:	February 9, 2011

This is to notify you that the Institutional Review Board has designated the above referenced protocol as exempt from the full federal regulations. This project was reviewed in accordance with all applicable statuses and regulations as well as ethical principles.

When the project is finished or terminated, please complete the attached Notice of Completion form and send it to the Board via e-mail at irb@memphis.edu.

Approval for this protocol does not expire. However, any change to the protocol must be reviewed and approved by the board prior to implementing the change.

Brian Schilling

Digitally signed by Brian K. Schilling
DN: cn=Brian K. Schilling, o=The University of Memphis, ou=IRB, email=bschllng@memphis.edu, c=US
Date: 2011.02.15 14:42:14 -06'00'

Chair, Institutional Review Board
The University of Memphis

Cc: Dr. Barbar Mullins Nelson

Appendix H: IRB Universidad Francisco Marroquin, Guatemala

UFM
universidad
FRANCISCO MARROQUIN
FACULTAD DE MEDICINA
6 Avenida 7-55, zona 10 • Guatemala, Guatemala 01010
Teléfonos / *Telephones* (+502) 2362-8711, 2334-8327 • Fax (+502) 2334-8329

Guatemala 25 de Noviembre 2008

Doctor
Federico Antillon
Director Medico/ Unop Guatemala
Presente

Estimado Dr. Antillon

Por medio de la presente y de la manera más atenta, me dirijo a ustedes, para informarles que en sesión realizada por comité de Ética fue revisado y autorizado el Protocolo de investigación, "Evaluación de la eficacia del Programa Educacional sobre la Seguridad Alimenticia (FSEP) utilizando un folleto educacional para una población de bajo alfabetismo"

Sin más por el momento quedo de usted,

Atentamente,

Dr. Edgar López Álvarez
Secretario
Comité de Ética

ELA/eg

COMITE DE ETICA
FACULTAD DE MEDICINA
UNIVERSIDAD FRANCISCO MARROQUIN
GUATEMALA, C. A.

Appendix

I: IRB Hospital Nacional de Niños Benjamin Bloom, El Salvador

COMITÉ DE ÉTICA EN INVESTIGACIÓN CLÍNICA (CEIC)
HOSPITAL NACIONAL DE NIÑOS BENJAMIN BLOOM
San Salvador, El Salvador, C.A.
Grupo de Revisores Institucionales (IRB) # IRB00004097 - FWA00006645

San Salvador, viernes 15 de agosto de 2008

Angélica Hernández
Enfermera Educadora
Dpto. Oncología, Hospital Bloom
San Salvador, El Salvador

Enfermera Angélica Hernández:

COD: PIEN004-08 "EVALUACION DE LA EFICACIA DEL PROGRAMA EDUCACIONAL SOBRE LA SEGURIDAD ALIMENTICIA UTILIZANDO UN FOLLETO EDUCACIONAL PARA UNA POBLACIÓN DE BAJO ANALFABETISMO."

Por este medio se certifica que en respuesta a solicitud recibida el 14 de julio de 2008 a su petición para revisión expedita de protocolo de investigación referida, la cual según la constancia presentada ya esta aprobad por el Comité de Ética del St. Jude Hospital, que:

El Grupo de Revisores Institucionales (IRB) acuerda el día 13 de agosto de 2008 que:

Este protocolo es aprobado de forma expedita ya que es una investigación con riesgo menor que el mínimo y de llevarse a cabo de acuerdo a las especificaciones que están descritas dentro del protocolo, específicamente la realización de las encuestas en el área señalada, ajustándose a las pautas internacionalmente reconocidas para investigaciones en humanos, y de una manera que atienda a los principios éticos precisos a la misma.

Se confiere excepción de consentimiento escrito tanto para los padres, familiares o encargados a ser encuestados según las proposiciones expresadas en el protocolo, ajustándose terminología más adecuada para el entendimiento de los encuestados y evitar el uso excesivo de imágenes que confundirían al encuestado, en especial aquellas que estén relacionadas con los objetivos del estudio. De igual manera se le pide que atienda esta y otras peticiones entregadas en documento que se le anexa y que sean trascendentales que las incorporen al protocolo antes de iniciar el estudio.

Cualquier modificación de las condiciones originales del protocolo debe ser informado por escrito para conocimiento y aprobación del Grupo de Revisores Institucionales (IRB), así mismo cualquier efecto adverso o lesión que se diera en los participantes en el transcurso de la investigación.

Debe notificar seguimiento y finalización de la investigación, así como proporcionar una copia del informe final.

Atentamente,

Dr. Sergio Roberto Parada Bridge
Presidente del Comité de Ética en Investigación Clínica

CC. / Archivo